The ultimate goal of palliative care is to improve quality of life for patients and families facing life-limiting illness. It is not dependent on prognosis and can be delivered at the same time as disease-modifying treatment. The success seen in the provision of palliative care to people with cancer provide an indication of what can be achieved by vision, leadership and community engagement. It is time for us to extend palliative care beyond cancer in order to ensure that people with heart failure also receive effective symptom relief, relief from worry and depression, carer support, careful communication and care planning. This action research report describes our organisations’ efforts to deliver on this vision.

We would like to gratefully acknowledge the support of the Irish Hospice Foundation, the Irish Heart Foundation and Baxter who provided the financial assistance to make this project possible. We would also like to thank the patients and their families who provided us with such valuable feedback and learning.

Action Research Steering Committee, 2014.
Heart Failure

Heart failure is a condition where the heart function is impaired and the heart fails to pump blood effectively around the body. It can occur suddenly, although it usually develops over a period of years. The most common causes of chronic heart failure are coronary heart disease and prior myocardial infarction, hypertension and diabetes. Although the incidence of new cases of heart failure may be stabilizing, the overall prevalence of heart failure is rising, due to improved survival rates from acute cardiac events, and therapeutic advances such as mechanical assist devices. The prevalence of heart failure in the developed world is approximately 1%, but much higher in older people, with an estimated prevalence of 4-6% in those over 70 years of age.

The trajectory of heart failure is unpredictable and up to half of patients die suddenly. Patients with heart failure may experience episodes of decompensation of heart failure; while many will recover from these episodes, unfortunately others will not regain their previous functional status. More recently, therapeutic advances such as left ventricular assist devices (LVADs) and implantable cardiac defibrillators (ICDs), can improve patients’ condition considerably, and significantly reduce their risk of sudden cardiac death. A very small proportion of patients may be eligible for, and receive, a curative heart transplant. People with heart failure frequently experience a wide range of symptoms, unfortunately not all of them are recognised or treated adequately (1).

It has been reported that 60-80% of individuals with end stage heart failure experience breathlessness, 42–82% fatigue, 41–77% pain, and 17–48% nausea (2.3). People with heart failure commonly experience psychological distress and Koenig showed that in a hospital based population of heart failure patients major depression was present in 36.5% and minor depression in 25.5% (4). Attention has been drawn to issues of communication and studies have shown that patients with heart failure report barriers to asking questions about prognosis and feel unable to raise certain issues with their doctors (5).

Palliative care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (6). In recent years, the potential role of palliative care in meeting the physical, psychosocial and spiritual needs of people with heart failure has been increasingly recognised. Indeed, the Scottish Partnership on Palliative Care (2008), the Heart Failure Association of the European Society for Cardiology (2009) and the Canadian Cardiovascular Society (2006) have all published Guidelines and position statements for palliative care in heart failure (7,8,9). It is timely therefore to look at this issue in the Irish setting.
This action research project arose from the findings of the Extending Access Study which sought to examine how palliative care could extend to people with Heart Failure, COPD and Dementia (10).

The report drew attention to the fact that heart failure services in Ireland are underdeveloped, and that there is an absence of a comprehensive service in primary care. It noted that a small number of community based heart failure service models are emerging around the country; however they do not have a formal palliative component. The Study identified a number of overarching and disease-specific recommendations in order to ensure that appropriate levels of palliative care are made available to people with COPD, dementia and heart failure. The recommendations related to issues of policy, education, service model development and research.

In particular, the Study recommended that a project group should be established to devise, plan and oversee a proposed Model of Care for patients with heart failure within a designated health location encompassing an acute general hospital, a primary care practice and a specialist palliative care service. This recommendation was based on UK experience which demonstrated how collaborative approaches between the Heart Failure, Primary Care and Specialist Palliative Care teams have facilitated access to all levels of palliative care for people with heart failure, supported professional development and enabled the establishment of shared care models (11, 12).

Cardiology and Palliative Care staff from the Mater Misericordiae University Hospital, Connolly Hospital, Blanchardstown and St Francis Hospice were chosen as the sites for an action research project aiming to develop the Model of Care in 2010.
Research question

“How best to devise, implement and evaluate appropriate palliative care responses for patients with heart failure and their families in hospital and the community in North Dublin?”
What is action research?

Action research is not easy to define. It is a style of research rather than a specific methodology (13). Action research is:

“A participatory, democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes, grounded in participatory worldview which we believe is emerging at this historical moment. It seeks to bring together action and reflection, theory and practice, in participation with others in the pursuit of practical solutions to issues of pressing concern to people” (14).

Why action research?

The strength of action research is that it looks at a practical problem and tries to generate a solution. It is a cyclical process that involves planning and taking action with reflection and evaluation (15,16). An advantage of action research is that many action research cycles may be running at the same time. Action research had been found to be effective in closing the theory-practice gap, in facilitating collaboration for strategic change and to be suited to small-scale projects to effect change within health settings.

Unlike traditional research paradigms, where the people who provide the data are variously seen as subjects or respondents, the underpinning philosophy of action research is not research “on” or “for” people but “with” people (17). Participation is central to action research: the participants must perceive the need for change and are willing to play an active part in the research and the change process (13).

Methodology

What is an action research cycle?

A cycle consists of:
- Understanding the setting,
- Planning Actions,
- Taking Actions and
- Evaluating Actions.

In the first step of the action research cycle, the stakeholders of the project collectively engage in understanding their setting and constructing what the issues are. Stakeholders consider the issues carefully and thoroughly because action is planned and taken on the basis of the constructed issues. However, it is accepted that construction of the issues may be provisional and may change in later iterations of the action research cycle as stakeholder understanding evolves.

Planning action follows from the exploration of the context and purpose of the project, the constructing of the issue, and is consistent with that. Action planning may focus on a first step or a series of first steps.

In the ‘taking actions’ stage of the cycle, plans are implemented and interventions are made by the stakeholders in a collaborative manner.

The outcomes of the action, both intended and unintended, are next evaluated with a view to seeing:
- If the original constructing fitted,
- If the actions taken matched the constructing,
- If the action was taken in an appropriate manner,
- What feeds into the next cycle of constructing, planning & action (18)

Multiple action research cycles may operate concurrently with different time spans. Ultimately, there is a continuing spiral of steps, ‘each of which is composed of a circle of planning, action and fact-finding about the result of the action’ (19).
Action Research Process

1. UNDERSTANDING THE SETTING
2. PLANNING ACTIONS
3. TAKING ACTIONS
4. EVALUATING ACTIONS
A scoping study of the literature was conducted to identify the current state of the knowledge regarding integration of palliative care into disease management frameworks for heart failure patients. The framework of Arksey & O’Malley (20) was used to guide the process. The five stages of conducting the review were:

- Identifying the research question
- Identifying relevant studies
- Study selection
- Charting the data
- Collating, summarizing and reporting the results

The literature scope highlighted compelling evidence that patients suffering from chronic illness other than cancer do not always receive a palliative care approach to care or specialist palliative care that cancer patients receive (21, 22).

It suggested that Primary Care and Cardiologists are often unsure how to integrate palliative care services into their practice (23, 21). Lack of appropriate palliative care education, training and work pressure were posited as barriers to palliative care provision.

The review drew attention to the recommendation that a shared approach between existing professionals and specialist palliative care professionals through patient information, communication and education (22).

A review of the records of patients who had recently died in the hospital was conducted in order to describe aspects of the processes of care at the end of life including:

- Whether death was expected or sudden,
- Use of pain and symptom control,
- Use of interventional therapies such as oxygen therapy, intravenous diuretics, inotropic support, implantable cardiovertor de fibrillators,
- Whether an end of life plan had been formulated,
- Whether a ‘do not attempt resuscitation order’ was in place
- Who the discussion of ‘do not resuscitate’ was made with,
- The place of death

This information was used to provide a baseline understanding of current practice.

Four focus groups were conducted involving 38 hospital and hospice staff members.

The transcripts were analysed to determine recurring themes and codes were developed based on the themes identified within the data.

Following this, the transcripts were coded according to these themes by identifying complete segments (e.g. sentences or paragraphs) as categories that had been isolated and defined during the course of the analysis.

Within the data, three major topics were identified. While each of these topics will be outlined as a separate area there is some overlap between the areas.

Further details on the focus group may be found on pages 18 & 32.

A total number of 148 questionnaires were distributed, with 96 returned and a response rate of 62% overall. Hospital A had a response rate of 67% and Hospital B, 56%.

Further details on the survey may be found on page 16.

Part 3: Attitudes towards patients with a life limiting illness was also assessed using a 13-item questionnaire and responses were obtained on a 10-point Likert scale, with one indicating strong disagreement and ten indicating strong agreement with each item.
Survey Findings

Findings

Respondents showed a strong appreciation for the importance of palliative care provision for patients with heart failure. A significant majority considered care of the dying patient to be a rewarding job and interactions with specialist palliative care teams were considered to be almost universally positive. Staff felt competent in the management of such practical tasks as using syringe driver infusions and also demonstrated a sound knowledge of use of analgesics. However, they were aware of shortcomings in other aspects of their knowledge base and skill set. 69% stated that they had an incomplete understanding of the principles of palliative care (only 21% identifying improvement of quality of life as the goal of palliative care) and 45% felt that they had inadequate communication skills. Particular difficulty in this area was noted by staff for whom English was not their first language. Staff were very keen to address these deficits however and 94% expressed an interest in engaging with further palliative care education. Of some importance, 49% of staff commented that they did not receive any support in their workplace following the death of a patient.
Focus group findings

“To move away from the heroics of trying to save someone’s life and [instead] trying to use that time to look after them…”

Role of palliative care

Participants echoed the survey finding, stating they felt that patients with heart failure would benefit from palliative care provision. Although they recognised that palliative care could be integrated early in the disease trajectory, staff mainly spoke of the role of palliative care as moving from a focus of care on interventional treatment to one that aims to:

• Improve quality of life
• Improve symptom control
• Ensure dignity at the end of life

Participants also pointed out that education and support of family members in their roles as carers were important aspects of palliative care provision.

Requirements

Participants had a number of suggestions as to what useful strategies or processes would help them to meet the palliative care needs of people with heart failure:

• Role delineation - having a clear understanding of the roles and responsibilities of the different specialities in order to promote effective team working
• Education on heart failure management for palliative care staff
• Education on palliative care management for heart failure staff
• Guidelines or algorithms to support clinical practice
• Improved communication about nature of condition, treatment options and

Requirements, ctd

prognostication for people with advanced heart failure and their families

• Improved communication with family and provision of family support
• Early integration of palliative care into the disease trajectory and ‘normalising’ the process of introducing the palliative care team
• Access to appropriate environment and equipment e.g. appropriate seating, family room in the hospital, community supports

Overall, participants had positive experiences of working with patients with heart failure and palliative care needs. Staff viewed palliative care as an important service for heart failure patients and their families, and felt that it offered a much needed level of support and comfort. Among key recommendations made by interviewees were the need for education and training for staff and the importance of communication between patients, families and team members. Staff emphasised the importance of education that was experiential and practice based rather than theoretical. Participants drew links between the patients’ experiences and those of their families, suggesting that offering supports and services for families was viewed by participants as a key aspect of providing quality palliative care to this population.

Threats

Participants drew attention to current limitations in service provision and were concerned that these gaps would impact negatively on their ability to provide palliative care. Staff said that it was important to ensure gaps in heart failure service provision were addressed and that adequate resources were made available to permit expansion of palliative care services to the population of people with heart failure.

There was some concern that palliative care would be inappropriately drawn to compensate for gaps in heart failure services. Participants were also concerned that public understanding of palliative care as being synonymous with cancer and with death could limit the willingness of patients to receive palliative care.
Planning actions

The Action Research Project Group reflected critically on the literature and collected data and considered its implications for practice in order to identify opportunities for change. The healthcare environment is a complex one and it quickly became apparent that a wide range of issues needed to be addressed in order to effect change in a sustainable manner.

The Group used this evidence and personal knowledge of their work and context to formulate strategies which were grouped into four areas:

1. Education activities
2. Communication activities
3. Partnership activities
4. Organisational activities

The group ‘began small’ starting with a core group of collaborators working on minor changes which were expected to be relatively easy and quick to manage. Gradually, the community of participants was widened so that it included more and more of those involved and affected by the practices in question. The wider group then addressed more extensive patterns of change. Throughout this process, the research officer had a valuable role to play as principle change officer. She also ensured that records were kept which described what was happening as accurately as possible and she collected and analysed the groups judgements, reactions and impressions about what was happening.
Education activities

Staff from the Education Departments of the Mater and St Francis Hospice provided valuable support in the development and production of the educational activities. The potential benefit of staff education and training was clear to the project team from the outset.

However, the educational activities also offered an important way of creating relationships with, and promoting collaboration between the different professional groups involved in the project. This was because cultural values and differences were safely addressed in the shared learning environment. This afforded staff the opportunity to expand their roles, understand the viewpoints of others and their organisational cultures.

In turn, this enabled them to work more effectively across professional and agency boundaries.

Examples

Feedback on survey

Case-based teaching

Description:
The statement by Sir William Osler that ‘Medicine is learned by the bedside and not in the classroom’, still has resonance over one hundred years later. The Palliative Care team contacted the Cardiology team following each consultation in order to exchange information, discuss management plans and offer the opportunity to share learning about the proposed palliative care interventions. The dialogue between the two teams was particularly useful because it was grounded in the practical realities of the problems experienced by patients and families.

Local study days

Description:
A joint study day was held by the Cardiology and Palliative Care teams in October 2011. This was well attended by hospice and hospital staff. A number of ‘outside’ delegates also attended providing useful opportunities for knowledge exchange and networking. Cardiology and Palliative Care staff also presented at North Dublin GP Educational session and this meeting highlighted the importance of considering the primary care dimension to any model of care developed between cardiology and palliative care services.

Conferences

Description:
Abstracts and posters were submitted to Palliative Care and Cardiology conferences in Ireland over the course of the project. The Irish Hospice Foundation funded action research projects in respiratory and dementia care at the same time as this heart failure project, and opportunity was taken to make joint presentations at a national palliative care conference (Kaleidoscope) and an international conference in Vienna in 2011.

Attendance at conferences afforded staff the opportunity to share thoughts and experiences with others, to step back and reflect on progress to date and to learn from others in similar situations.

E-learning platform

Description:
Increasing pressures on hospital and community based staff has resulted in fewer opportunities for provision and attendance at face to face training. As a result, an online learning programme was developed in order to provide an alternative to face to face training. The development of an e-learning platform provides a flexible delivery system which allows for study in peoples own time. The e-lectures are hosted on the St Francis Hospice website and it is planned that further lectures will be added to the site with time.

The site can be accessed by the following steps:
1. Go to http://elearning.sfhi.ie and click on the e-learning button in the bottom right hand corner
2. If you are visiting the e-learning site for the first time, then you need to register. Otherwise, click ‘login’ at the top right hand side of the page
3. After registering, you will receive notification in your email that your account is activated. You can then access the web content for free.

Education activities

Reciprocal education

Description:
The challenges of the economic environment has meant that it has been difficult for staff to obtain funding to engage in educational activities. With this in mind, the hospice offered Mater staff members free attendance at a number of palliative care educational events. Likewise, the Mater provided complementary educational sessions on the management of heart failure to palliative care staff. In this way, staff from both disciplines were able to participate in continuing professional development at no additional cost. They grew in knowledge and confidence and were also afforded additional opportunity to network and build professional relationships. Participation in such events in turn stimulated further interest among staff. One of the cardiology ward clinical nurse managers has undertaken a Masters course in Palliative Care, and has brought her learning back to the hospital setting where she continues to drive quality improvement in clinical practice on the Sacred Heart ward.

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Taking actions | 23

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Communication activities

The analysis of the questionnaire and focus group data identified a demand to enhance the communication skills amongst staff so they could sensitively address and respond to the palliative needs of patients in their care. This finding is one that has been noted to be a common refrain in published literature and its importance cannot be over-estimated.

The project officer used this information to plan a number of action cycles: enabling key staff to participate in an ‘end-of-life communication skills’ workshop; the development of a patient information poster and a booklet on palliative care in heart failure. The project officer also actively facilitated dialogue between project team members in order to nurture a perspective and connectedness that stimulated and challenged thinking in relation to models of care and provided a forum in which innovative approaches to care could be identified.

Examples

Communications training

Description:
Final Journeys is an introductory programme aimed at enhancing the quality of the interactions between patients at end of life, their families and hospital staff. It was devised by the Hospice Friendly Hospitals Programme in association with the Health Service Executive. Communication issues had been highlighted as being of particular concern to focus group and survey respondents but there was high satisfaction with attendance at this programme and staff indicated that they felt more confident in their abilities following training.

Patient information

Description:
A poster and patient information leaflet on palliative care for people with heart failure was developed. Throughout development, commentary was actively sought from patients. Although staff had concerns about use of the term ‘palliative care’, feedback on the final version from 14 patients and 6 relatives indicated that:
• Only 55% had heard of palliative care previously
• 70% were encouraged to read the poster by inclusion of the term ‘palliative care’
• 90% felt it was explained well

Joint consultations

Description:
The Heart Failure Clinical Nurse Specialist frequently accompanied the Palliative Care team on patient consultations. In this way, the Palliative Care team benefitted from the knowledge and therapeutic relationship that the Cardiology team had established. Also, the Heart Failure CNS gained knowledge of palliative care from observing the team in practice. Collaborative working between the teams was significantly strengthened through these joint consultations and there was conscious effort to use each interaction as a ‘teaching moment’.
Partnership activities

The quality of the care given by health and social service professionals depends not only on their individual skills, knowledge and experience, but also on how those individuals work with each other (26). It has been noted that ‘interprofessional working is not about fudging the boundaries between the professions and trying to create a generic care worker. It is instead about developing professionals who are confident in their own core skills and expertise, who are fully aware of and confident in the skills and expertise of fellow health and care professionals, and who conduct their own practice in a non-hierarchical and collegiate way with other members of their working team, so as to continuously improve the health of their communities.’ (27). It is recognised that numerous barriers to interprofessional working commonly exist so it is important to take a pro-active approach to building partnerships in the healthcare setting.

Examples

New relationships

Description:
The development of relationships was central to the success of the project. Members of the project team not only forged deeper relationships with each other as part of the action research process, they also gained access to the each others’ professional networks. This meant that new working relationships were established which further enhanced knowledge and understanding of the contexts of cardiology and palliative care.

Project meetings

Description:
The first condition necessary to foster action research and encourage change is for stakeholders to review and restructure their power and authority relationships (Mills, 2003). As they met, the team developed a shared language and came to a clearer understanding of each others’ roles and objectives. The meetings provided opportunities for difficult questions to be asked and answered and these questions led to conversations about responsibilities and leadership. Although not always easy, the meetings provided valuable fora for team development.

Ethical review

Description:
Left ventricular assist devices (LVADs) represent a therapeutic advance in the management of CHF. However, their use may also pose ethical challenges. Studies have shown that some family members of LVAD recipients are concerned that palliative care teams have an incomplete understanding of the functioning or implications of LVADs. As palliative care and heart failure services become increasingly integrated, an understanding of the ethical issues surrounding LVADs is essential. The input of an ethicist in an ethical case review proved to be a significant support to team learning.

End of Life Audit

Description:
The Mater Hospital participated in the pilot of the Irish Hospice Foundation End of Life Audit tool. The Action Research team used this as an opportunity to gain knowledge about the care they were providing to patients with heart failure who died in the hospital, and to learn from this experience.

The audit tool was used to review the quality of end-of-life care provided. Information was gathered during a meeting which was open to all members of staff who were involved in any aspect of the person’s care during the last week of life. A facilitator led the audit meeting and created an atmosphere which was constructive, reflective and non-threatening in order to facilitate reflection on practice. Later the facilitator entered anonymised data into a central database. Bereaved carers were also mailed a survey which invited them to comment on their perceptions of the quality of care provided. This anonymised data was also entered into the central database. Bereaved carers were also mailed a survey which invited them to comment on their perceptions of the quality of care provided. This anonymised data was also entered into the central database. Bereaved carers were also mailed a survey which invited them to comment on their perceptions of the quality of care provided. This anonymised data was also entered into the central database.

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Competency framework

Description:
The focus groups highlighted the importance of staff having the right attitude, skills and knowledge to be able to provide palliative care. Work was carried out by the National Clinical Programme for Palliative Care in the Health Service Executive to address this issue and a member of the Action Research Group participated in the project. A national palliative care competence framework was produced that describes core competencies in palliative care that are common to all disciplines, whilst also detailing individual competencies for each health and social care discipline. Competencies are described at three levels of practice - ranging from Palliative Care Approach skills, to General Palliative Care skills, to Specialist Palliative Care skills. The Framework can be used as a means of informing continuous professional development and performance appraisal. The document can be found at www.hse.ie/palliativemcareprogramme

Role delineation

Description:
The focus groups also highlighted the importance of staff knowing how best to work together to ensure that care is provided in the best way possible. In order to ensure that patients can transfer seamlessly between care settings or service levels when their condition or circumstances change, the place and relationships of individual service providers within the broader mosaic of palliative care provision must be clearly described. Work was also carried out by the national Clinical Programme for Palliative Care in the Health Service Executive to address this issue. A member of the Action Research Group participated in this process which resulted in the development of a Role Delineation Framework. Both the Competence Framework and the Role Delineation Framework may be found on the clinical programme website at:

https://www.hse.ie/palliativemcareprogramme
Organisational activities

It was recognised that it would be necessary to take both a ‘top down’ as well as a ‘bottom up’ approach to change management in this project as organisational structures were seen to be important influencing factors in staff’s ability to meet the palliative care needs of patients with heart failure.

A number of organisational barriers were identified. It was acknowledged that it would be difficult to address some of the most common (heavy workload, high patient acuity and lack of time) due to resource limitations. However, other barriers which related to process issues (e.g. access policies, care pathways) could be addressed without additional resource utilisation.

The strong, supportive leadership demonstrated by managers at all levels of the organisations involved was key to enabling this type of change.

Examples, ctd

Design and Dignity

Description:

The Design and Dignity Grants Scheme arises from the Hospice Friendly Hospital Programme. The Scheme aims to demonstrate how good design positively impacts the culture of care for patients at end of life and their families. Recognising how deeply people are affected by their surroundings, the Design & Dignity Project has developed a range of ‘exemplar’ projects within acute hospitals. The exemplar projects demonstrate how effective design of hospital spaces can transform the experience of patients and their families and set the standard for other hospitals to follow.

Following a careful planning process, an eight-week Day Hospice Programme was developed by the multidisciplinary team specifically for patients with heart failure and palliative care needs.

Appropriate patients are identified by the Heart Failure Team and then referred for assessment by the Day Hospice team prior to enrollment in the programme. The assessment takes place in St. Francis Hospice approximately 1 week before commencing the programme. The purpose of the assessment is to gather baseline data on functional ability (e.g. 6 minute walk test, Minnesota Living with Heart Failure Questionnaire, Palliative Outcome Score), introduce the patient to the facility and members of the team and then referred for assessment by the Day Hospice Team.

The programme then consists of:

• Carer support/education.
• Engagement in future care planning.

Symptom management is achieved by pharmacological and non-pharmacological methods. The involvement of physiotherapists and occupational therapists is of critical importance and patients engage in a group exercise programme with a particular focus on breathing techniques and on learning fatigue and breathlessness management strategies.

Follow-up data is collected at completion of the programme in order to allow for an evaluation of the programme’s effectiveness in the future. To date, patients have been referred to the programme and results from the evaluation of this small sample revealed positive outcomes for patients. Formal reporting on outcomes and effectiveness will be made once sample size is sufficient.

Day Hospice Programme for patients with heart failure

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Evaluating actions

Focus groups

A repeat series of focus group interviews was held with participants. The interviews indicated that staff felt that significant learning had occurred that had translated into measurable patient benefits. The process of change management had been more challenging and time-consuming than had originally been envisaged but the majority of staff were not discouraged by this. This was particularly true of staff working in areas where the project had led to tangible outcomes e.g. acquisition of new skills by staff or instances where patients with heart failure had been successfully admitted and cared for in the hospice.

Chart Review

We identified 22 patients (age range 40 – 90 years) with advanced HF who were under care of the cardiology team who received input from the palliative care hospital team in the two year period following commencement of the project. 21 of these patients died and 1 patient proceeded to a successful heart transplant. Trigger for palliative care involvement was documented as symptom management or end of life care. Time from referral to palliative care to death was between 2 hours and 158 days. Family meetings were documented in 18 patients (82%). Preferred place of death was documented in 11 patient’s charts – these were hospice (4), home (4), nursing home (2) and hospital (1). The 3 patients who had an expressed wish for place of death in hospice died in hospice, however of the remainder, 14 died in our hospital, 2 were transferred to local hospitals to be closer to family for end of life care, 1 patient was discharged and readmitted to another hospital where they subsequently died and 1 further patient died in hospice. Senior staff involvement in decision making was demonstrated with 100% of documented decisions regarding ICDs involving the consultant. Medications for breathlessness management were reviewed. 10 patients (45%) had oral opioids prescribed and 8 patients (36%) had an oral benzodiazepine prescribed. A subcutaneous infusion was used towards the end of life in 11 of the 14 patients who died in the hospital.

Peer Review

Peer review is the process of subjecting an author’s (or team of authors) work, research, or ideas to the scrutiny of others who are experts in the same field. Peer review also offers staff an opportunity to both give and receive support, and to network with those involved. In particular, the ‘external lens’ of peer review allowed us to see how others perceived our performance and we incorporated those insights into our reflective practice. It proved to be a very valuable way of achieving perspective on the achievements and shortcomings of our action research project. We received peer review feedback from a variety of sources- conference presentations, workshops and journal editors (e.g. a case report was accepted for publication by BMJ Palliative and Supportive Care). We found the peer review process to be a constructive one. It fostered a positive atmosphere around the notion of clinical practice development and evaluation, and helped further develop collegiality.
Focus group findings

“*I think attitudes have just changed, there’s no shame in palliative care, you know, maybe before palliative care was like a death wish, you know…end of life, but not, like it’s symptoms, or dealing with patient comfort, the patient is the priority of it all…there’s a taboo, you’d hate using the word palliative because you know that means the end, but now sometimes it doesn’t mean the end, I mean the end is nigh for all of us, but it’s more, I don’t know, it’s about patient comfort.*”

Awareness of Changes
Participants indicated a good awareness of developments in relation to the provision of palliative care for patients with heart failure. Importantly, staff in both the acute and hospice care settings were increasingly aware of what happened within the other organisation, with key stakeholders from the different services having visited each other in their respective sites. While it was not the case that palliative care was never delivered prior to the action research project, the delivery of palliative care was perceived to be more timely and effective now and staff had grown in their confidence in being involved and providing such care.

Strengths
During the focus group discussions, staff in both settings identified what has worked well in the project:
1. There had been a shift in conceptualisation of palliative care: Participants in the hospital reflected upon how the concept of palliative care had broadened from previously being considered as an approach just used to treat people with malignant cancers or for end-of-life care, to now being conceptualised as an approach useful for symptom management or to improve patient quality of life, and for those with illnesses other than cancer. By re-framing palliative care as being about patient comfort and an approach to symptom management, fears for patients could be allayed and staff in the acute setting felt more at ease in discussing palliative care.
2. Communication in the hospital had improved.

Strengths, ctd
Staff felt that it was easier to introduce the subject of palliative care and noted that they were more skilled in engaging with patients.
3. Networking and relationships had strengthened & hospital staff felt supported providing care in an area that they had previously found challenging.
4. There was improved recognition of patients who might benefit from incorporating a palliative care approach into their management, and more timely referral to specialist palliative care.
5. The organisation of care had improved. Patients now could access the hospice in-patient unit and Day Care programme. Discharge planning also had improved with staff increasingly considering what supports would be needed.
6. The quality of care provided to patients and their families had improved with holistic care provision.

Areas for ongoing work
Participants were enthusiastic about progress but were aware of the need for further work. There was a commitment that this was a ‘work in progress’ and staff identified a number of areas that would benefit from further focused efforts. The continual need for education, training and reflection on practice was clear. It was felt that there should be particular effort to increase medical engagement in this. A particular focus on recognition and response to psychosocial needs, and care planning (including the issues of resuscitation and advance care planning) was highlighted for all members of the multidisciplinary team. Staff were aware that developments had mainly occurred in the hospital and hospice settings and that attention should now turn to the community setting and developing improved systems there.

Thirty-six staff members participated in four focus group discussions. The focus group discussions were guided by eight key questions, although narratives were followed up, where appropriate:
1. Were you aware that efforts had been underway in the last two years to improve the quality of care that we provide to people with heart failure?
2. Have you seen any changes in the way that we provide care to patients with heart failure and palliative care needs in recent years? If so, what kind of changes?
3. What changes worked particularly well or were of particular importance? (Probe)
4. What changes didn’t work so well?
5. How would you describe the quality of care we provide to patients with palliative care needs?
6. What things do we do well?
7. What things could we do better?
8. Have you any suggestions as to further improvements that could be made?
Next steps

Understanding, planning, taking actions....

We began this project by asking the question “How best should we devise, implement and evaluate appropriate palliative care responses for patients with heart failure and their families in hospital and the community in North Dublin?”. We hoped that the process of finding answers would lead us to the development of a model of care for people with heart failure and palliative care needs and ensure measurable improvements in the care that we provide to patients and their families.

A model of care is a multifaceted concept, which broadly defines the way health services are delivered. Optimally, the development of a model of care should be ‘multifaceted and multidisciplinary, incorporating the best available evidence from patient-centered research with the needs and preferences of individuals, communities, health professionals, policy makers, funding agencies, professional organisations and underpinned by sound theoretical and conceptual principles’ (28). The establishment of new models of care is demanding as it often involves the development of skills, systems, processes and resources to close the gap between research evidence and clinical practice.

Palliative care provision for people with heart failure is a relatively new area of clinical practice and one that is not associated with a significant evidence base. More generally, it has been noted that much of the literature examining the effectiveness of palliative care interventions to improve patient outcomes demonstrates variable findings, quality deficiencies, vaguely defined interventions, and variable measurement tools and reporting (28). It is not surprising, therefore, that our work to date has been particularly iterative in nature as we have approached each cycle de novo and required significant time to develop the skills, systems, processes and resources required to promote acceptance, adherence and integration to practice changes. However, the successful implementation of early stage initiatives has created a positive environment and provided the basis for continued exploration of model elements.

Reflection and evaluation has been intrinsic to the action research process, and the interim review provides us with the opportunity to take a more considered view of progress to date. At this point in the research cycle, we consider that we have described and understand the current state of play of palliative care provision for patients with heart failure in our local context. We recognise our areas of strength in service provision but acknowledge areas of inadequacy where patient and family needs are not met optimally. While we have achieved experience and success in carrying out Plan-Do-Study-Act (PDSA) cycles in which tests of change were carried out, on reflection, we could have been more rigorous in measuring outcomes in order to demonstrate when change occurred and whether improvements were noted. We will carry this lesson forward in the next stages of the project.

Additionally, reflection on the information and outcomes of the project to date has led to a re-definition of our approach and greater clarity in the vision of the integrated heart failure-palliative care service and how we are going to achieve that. We clearly understand that the definition of optimal palliative care provision in heart failure management requires integration with the established methods of chronic disease management and ownership by the cardiology team. We have noted that the action research cycles that have been carried out so far relate to many of the elements of the Chronic Care Model (CCM) developed by Wagner and colleagues (1999). However, review of the CCM has led us to recognise areas of where we have failed to develop practice and also has led to the realisation that we have failed to consider the delivery system as a whole and demonstrated relative neglect in integrating the contributions of primary, specialized and social care organisations.

In the next phase of our work, we plan to use the conceptual framework of the CCM to organise the action research cycles, thus providing a coherent description of multicomponent system level intervention that provides a methodology for integrating palliative care in the chronic disease management of heart failure. The following pages will discuss this approach further.
Words of advice!

Lessons we have learned... and things others might find useful if engaging in similar work...

Action research has been widely used as a method to stimulate learning processes in organisations and to engender organisational change. Much has been written on the subject, including guidance on overcoming barriers and achieving change. In retrospect, the problems we encountered should not have been unexpected and the lessons that we have learned are by no means original. However, we include them in the report as they may serve as useful cautionary tales to others who are seeking to engage in a similar project to our own.

1. Careful thought should be given before the project begins to ensuring that the organisational capacity is in place to sustain the project over its duration. The following elements should be regarded as prerequisite rather than operational ‘luxuries’:
   - Ensuring adequate and consistent opportunities are scheduled in the busy clinical week for engaging in the action research project (preparing, carrying out actions, gathering data, analysing, dialoguing and engaging collaboratively as a team).
   - Understanding what the ‘power relationships’ in your workplace are, securing support wherever possible, and involving critical individuals even when their support is not given at the outset.
   - Ensuring a support system is in place in the form of an outside individual (or individuals) who are experienced in action research and change management.

2. At the outset, consider the scope of the project and those of the action cycles. The focus and level of participation planned should be dependent on the level of support, needs, and interests of the site. Once the scope of the project has been decided, then this needs to be clearly communicated to stakeholders so that people have realistic expectations about what is involved, the timelines of the project and an explicit understanding of what will be achieved.

3. Do not rush into action cycle phase of the project. Time spent understanding the environment, building mutual trust and support, and planning the actions is time well spent.

4. In the enthusiasm to engage in the action phase of the cycle, it is easy to give too little time to the consideration of what outcome data you will be collecting to study responses or outcomes. Determining impacts is often a challenging task in the healthcare setting due to the complex nature of the environment and interventions. It is particularly important, therefore, that the outcomes you select are easily measurable, valid, and reliable. Conducting a quick pilot of data collection in advance of engaging in action cycles can yield valuable information in this regard and will ensure that you are able to monitor the progress of the project with confidence.

5. Consider engaging on smaller scale actions or ones that can be rapidly achieved at the beginning of the project in order to build confidence and momentum in the process.

6. Ensure you have a communications strategy in place for the team to present their progress and findings to stakeholders at regular intervals over the lifespan of the project.
Next steps

Making palliative care provision manifest within the Expanded Chronic Care Model...

The Irish health care system, common with most international health systems, was designed to address acute illness rather than chronic disease. Care tends to be reactive—responding to acute health problems when they present and this is ill-suited to the management of chronic diseases such as heart failure. Internationally and within Ireland there is significant interest in redesigning health care organisations and practice to improve the quality of care and to close the gap in care between what is known to improve outcomes in chronic disease management, and what is practiced.

The Chronic Care Model is perhaps the best known and most widely implemented framework which guides people with long-term conditions. The Chronic Care Model describes the necessary components for a delivery system that encourages and sustains productive interactions between patients and providers. These elements are the community, the health system, self-management support, delivery system design, decision support and clinical information systems. Evidence-based change concepts under each element, in combination, foster productive interactions between informed patients who take an active part in their care and providers with resources and expertise. The staff at the MacColl Center for Health Care Innovation at Group Health Research Institute developed the CCM in the mid-1990s; the Model was further refined in 1997, and again in 2003 to reflect advances in the field of chronic care both from the research literature and from the scores of health care systems that implemented the Model in their improvement efforts. In 2000, the Ministry of Health in British Columbia adapted the Model to fit the expanded role of government and community in the Canadian health care system and named it The Expanded Chronic Care Model. Since then, other provinces that include Alberta, Saskatchewan, and Ontario have embarked on similar quality improvement work using derivatives of The Chronic Care Model to redesign their health care infrastructures.

We consider that the Expanded Chronic Care Model (29) offers significant promise as a feasible and useful basis for practice redesign and that the principles of the Model for Improvement (30) provide a strategy to achieve change. The Framework can be viewed as a ‘roadmap’ to a chronic care delivery system that provides effective care and better health outcomes. Each ‘stop’ on the roadmap is linked to other stops. The Model for Improvement can be thought of as the vehicle by which practice and system changes are achieved and aligns to the action research process.

The CCM expresses the change concepts only generally in order to encourage flexibility and local creativity in their implementation. However, organisations frequently require concrete ideas and specific guidance in order to enable them to begin the quality improvement process. Our work to date has resulted in the development, description and implementation of a number of change concepts/system change ideas that can be used by other organisations to integrate palliative care and heart failure management. For example:

- **Element**: Delivery System Design,
- **Change concept**: Team practice,
- **Description**: Role delineation, training to develop additional competencies (cardiology, palliative care and primary care all identifying deficiencies), joint consultations with patients.

- **Element**: Self-management Support.
- **Change concept**: Patient education.
- **Description**: Development and implementation of patient information leaflets and posters.

The next phase of work will carry out further PDSA cycles aimed at filling some of the gaps in practice that have already been identified. Our work will be further refined and improved by more rigorous measures used to track the accomplishment of change. It has been noted that the CCM is not a quick fix or magic bullet; it is a multi-dimensional solution to a complex problem (31). Certainly, it has proved to be a longer and more involved process of change than we thought would be the case when we began with only a vision of better care for our patients. However, we hope that the description of our experiences will accelerate the spread of best practices and innovations in other organisations.
Appendix

The Heart Failure Information poster produced by the action research team may be found on page 41.

Additional project resources may be found at:

http://www.hospice-foundation.ie

http://www.sfh.ie/

http://www.mater.ie/

Ethical approval was granted by the Mater Misericordiae University Hospital, Connolly Hospital and St Francis Hospice for this study.

HEART FAILURE AND PALLIATIVE CARE

Heart Failure is a medical condition where the heart does not work as efficiently as it should. People are now living longer than ever before with this illness and most have an excellent quality of life. However, some have a more difficult course and may need extra support to help them cope with heart failure. This poster aims to help you know what palliative care means and how it may help you or your family.

What is palliative care?
When you have a serious illness, such as heart failure, you may suffer from physical discomfort such as shortness of breath, pain or nausea. You may also have feelings of psychological distress, such as anxiety or depression. Your healthcare providers will provide medical therapies to treat or manage your condition, for example, water tablets or blood pressure medications. However, you may also need to receive care that is focused on improving your quality of life while you are ill. This type of care is called ‘comfort’ or palliative care.

Who provides palliative care?
Your cardiology team and general practitioner can provide palliative care in most circumstances. If more intensive palliative care is needed, your doctor can refer you to the Specialist Palliative Care team for extra support.

The Specialist Palliative Care team is based here in the hospital and works in partnership with your usual doctors to provide the care that you need.

When should I receive palliative care?
Many people mistakenly believe that you can only receive palliative care when other treatments are no longer possible. Actually, palliative care can be provided to people of any age and at any stage of their illness.

You and your healthcare team are the best people to know when is the right time to introduce palliative care into your care plan. If this hasn’t been discussed but you would like to do so, then don’t hesitate to raise the subject with the cardiology team or your GP.

What can palliative care do for me and my family?
A focus on palliative care can help to:

- Provide relief from pain and other distressing symptoms,
- Provide you and your loved ones with emotional and psychological support and guidance,
- Plan for the future, including making plans for living as well as possible, based on your needs, concerns and goals for care.

More information about palliative care is available from the Heart Failure Team.

This poster was produced as part of the Palliative Care & Heart Failure Action Research Project and is displayed at outpatient Heart Failure Clinics at the Mater and Connolly Hospitals, Dublin October 2011.

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References


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During the project the following people developed the Day Hospice Heart Failure Management Programme:

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