

# **Patients' experiences of attending an adapted cardiac rehabilitation programme for heart failure in a day hospice**

Authors:

**H. Walthall**

**C. Roberts**

**D. Butcher**

**S. Schutz**

Abstract:

**Background:**

Heart Failure is highly prevalent with poor outcomes yet only a small proportion of patients receive specialist palliative care services.

**Aim:**

To explore if a programme focussing on support and symptom management of people with heart failure in a hospice environment would be acceptable and of benefit to patients.

**Methods:**

A pre/post intervention study design using mixed methods was used to evaluate the programme.

The programme was delivered in two-hour time slots over a period of 8 weeks. Participants completed 3 questionnaires pre and post and were interviewed within one week of completion. The study was conducted between June 2014 and January 2015.

**Findings:**

A response rate of 51.7% gave a final sample size of 12 patients. The questionnaire results showed a positive impact on participants' well-being and views regarding the use of a hospice, but a desire for greater focus on emotional support. Four key themes emerged from inductive qualitative analysis: *demystifying perceptions about hospice; positivity about well-being; learning together and consideration of end of life preparation.*

**Conclusion:**

This adapted programme provides a useful model for the increased integration of palliative care into the provisions for those living with advancing heart failure.

Study registration: ISRCTN01423876

**Key words:** heart failure, hospice, end of life, integrated care, palliative care.

**Key Points:**

- A structured and integrated programme with heart failure and palliative care teams improved the experiences and understandings of people with heart failure.
- People with heart failure benefit from interaction with others in a similar position.
- Exposure to a hospice environment challenges preconceptions among those living with heart failure.
- Preparation and discussion of end of life is needed earlier in the heart failure trajectory to support patients

**Continuing professional development: reflective questions**

- When should end of life discussions be addressed with patients with heart failure and their loved ones?
- What do you think about introducing day hospice support for patients with heart failure?
- How do you think we can reduce the feeling of isolation experienced by patients with heart failure?

**Introduction:**

Heart Failure (HF) is a highly prevalent syndrome, often with poor outcomes in a predominately in the older aged group (mean age of first admission 77.7 years) who have a number of comorbidities (National Institute for Cardiac Outcomes Research (NICOR), 2018). An estimated 26 million people worldwide suffer from heart failure yet only a small proportion are referred to specialist palliative care services.

Palliative care is an interdisciplinary approach to care that focuses on improving quality of life and reducing symptom burden (World Health Organisation (WHO), 2019), both of which are common care outcomes for patients at the end stage of HF. Evidence related to palliative approaches in HF is limited and presents a uncoordinated picture. Historically, palliative care referrals were made when active treatment options were limited and life expectancy was significantly reduced (MacIver and Ross, 2018), and the current evidence base illustrates limited palliative care focused communications with those living with heart failure (Rogers et al, 2017). Although uptake of palliative care services for HF patients is increasing and is comparable with other non-malignant chronic diseases (Wiskar et al, 2018) it remains significantly lower than those with a cancer diagnosis (Cheang et al, 2015).

Policy makers in Europe (ESC, Jaarsma et al, 2009), the United States (AHA, Yancy et al, 2013) Canada (Ezekowitz et al, 2017) and the United Kingdom (NICE, 2018) have published guidelines for the implementation of an integrated approach to care for patients with advanced heart failure, yet there is limited evidence demonstrating their impact on patient outcomes. Studies by Pattendon et al (2013) and Johnson et al (2012) have shown that an integrated approach encourages joint decision making with patients, family members and HF nurse specialists. This promoted better access to support services at the end of life, where death was more likely to occur in the patient's preferred place. Furthermore, communication is improved through better understanding of patients' goals and wishes when they near the end of life (McIlvennan and Allen, 2016) and improvements in symptom control, functional status, quality of life (Devi, 2011; Butrous and Hummel, 2016). The

recently published PAL-HF randomised clinical trial is the first longitudinal trial to show a palliative care intervention for HF patients at the end of life that has significant and sustained benefits for patients related to quality of life, anxiety and depression when compared to usual care (Rogers et al, 2017). Importantly there was no change in mortality rates, suggesting the palliative care intervention enabled a 'better' end of life experience for the patient.

Early planning end of life care is often seen as difficult to approach following diagnosis of HF due to the nature and uncertainty of the disease trajectory (McIllellan and Allen 2016). Many patients are managed by cardiology services who do not receive timely referrals to specialist palliative care services. This lack of referral could be due to misunderstandings about the services of specialist palliative care and hospice services. Palliative care focuses on improving quality of life and relieving suffering of patients and their families with life-limited illnesses and is based on clinical need rather than patient prognosis. Hospice care has a palliative focus at the end of life and is often provided in a dedicated and specialist environment (Kavalieratos et al, 2017). The two concepts are often seen as synonymous resulting in a lack of engagement with palliative care in HF management (Metzger et al, 2013). Both palliative care and hospice services encompass support for non-malignant life-limiting conditions, such as HF (World Health Organisation, 2014) and day hospice care is aimed at offering combined services to support people to live with their illness in the community.

Cardiac Rehabilitation programmes are offered to patients diagnosed with mild to moderate HF (Austin et al., 2005; Butrous and Hummel, 2016) early in diagnosis to help patients to live with HF, although this is not universal. Programmes focus on psychological and educational components of managing HF as well as exercise to improve functional capacity. The purpose of the programme is to increase self-care abilities as well as to decrease fear and uncertainty around the condition to enable the person to live with the condition (NICE, 2018). We sought to examine if an adapted cardiac rehabilitation programme delivered in a day hospice environment would bring together the support offered by a structured programme of education and support for HF with the expert assessment of

symptoms and psychosocial care for people entering the advanced stages of the HF disease trajectory.

**Aim:**

The aim of our study was to deliver an adapted cardiac rehabilitation programme for people entering the advanced stages of HF trajectory in a day hospice to see it was acceptable and of benefit to patients.

**Methods:**

Study Design

A pre/post intervention study design using mixed methods was employed to evaluate the 8 week programme delivered in a local day hospice. All participants completed three questionnaires before and after the programme and were interviewed within one week of the end of the programme. The programme was delivered twice to reduce the bias of one cohort's experience.

Intervention:

National guidelines by the British Association of Cardiovascular Prevention and Rehabilitation (BACPR,2012) for the delivery of cardiac rehabilitation programmes were followed. The programme was developed collaboratively by palliative care and heart failure nurse specialists and was delivered in a day hospice by specialist palliative care nurse specialists. One of the week's sessions was delivered with the HF nurse specialist.

**The exercise component:**

This was adapted from the British Heart Foundation's DVD 'Active heart, healthy heart' which offers a progressive exercise regime for people who have a diagnosis incorporating heart disease.

Participants undertook gentle chair based (seated) exercises including warm up exercises which involved stretching and moving (through circular movements) joints and limbs (including arms, elbows, shoulders, wrists and legs, ankles, knees and toes). The pace of the session each week was

determined by the group and adapted accordingly. At the end of each exercise session there was time for recovery, social interaction and refreshments.

**The educational component:**

Topics covered are outlined in table 1.

Table 1: Outline of the programme

Week	Topic	Delivered by
1	<b>Keeping on the move.</b> Energy conservation and lifestyle adjustments to breathlessness	Palliative Care Nurse Specialist
2	<b>Avoid thinking traps.</b> Relaxation verses anxiety	Palliative Care Nurse Specialist
3	<b>Nutrition for energy</b>	Palliative Care Nurse Specialist
4	<b>Making the most of every day.</b> Distraction and diversion	Palliative Care Nurse Specialist
5	<b>Successful snoozing.</b> Sleep and fatigue	Palliative Care Nurse Specialist
6	<b>Implantable cardiac defibrillators and pacemakers and review of medication</b>	Heart Failure Nurse Specialist
7	<b>What does the future hold?</b> Advance care planning I really do have choices.	Palliative Care Nurse Specialist
8	<b>Who's who when I need help?</b> Community and hospice services and how to access them	Palliative Care Nurse Specialist

After each of the educational sessions participants were encouraged to continue informal conversations, undertake art therapy or to use the hospice facilities with a member of the hospice nursing staff. The educational component lasted on average 20 minutes with each educational session planned for 45 minutes but was either longer or shorter depending on group interaction.

**Sample/Participants**

Participants were recruited through convenience sampling from a geographic locality in the South East of England where the community HF nurse specialist identified potential participants. Inclusion criteria included a diagnosis of Chronic HF assessed as NYHA class III/IV; congruent with the Local Strategic Network's criteria for 'End of Life'; expected survival was greater than 10 weeks from the start of the programme and able to demonstrate capacity to make informed choices. Participants

were excluded if they were unable to read (or have translated) English or unable to exercise at the level required.

The community HF nurse specialist discussed the study with potential participants. If they wanted to be involved they returned an expression of interest in a stamped addressed envelope to the research team. The lead researcher (HW) met the participants one week before the commencement of the programme in their preferred venue (usually their own homes), explained the programme and gained informed consent. Each participant was assured of their anonymity and data protection and were assigned a cohort number. At the same meeting the participants completed 3 self-reported questionnaires.

Mobility needs were discussed with each participant prior to the programme commencing. Each week participants were collected from their home to attend the programme by a hospice volunteer driver.

#### Data Collection:

The three questionnaires included the Minnesota Living with Heart Failure Questionnaire (MLHFQ) (Rector et al, 1993); Emotion Thermometer (Gessier et al, 2008) and Foot in the Door Assessment tool (Stananought et al 2011). The questionnaires were chosen due to previous use in research with a HF or palliative care patient group. Each questionnaire was completed before and within one week of the completion of the programme, where the lead researcher (HW) arranged to meet the participant at their home. Prior to interview, continued verbal consent was ascertained to ensure the participant remained in agreement to be interviewed. No participants revoked consent. Interviews were semi-structured based on an interview schedule that focused on the course structure, the course content and the environment in which it was delivered. Some of the participants (8/12) had relatives present during the interviewing, but they did not contribute. Interviews took between 31-55 minutes.

## Data Analysis

Questionnaire data were analysed using IBM SPSS statistics version 21. Scores before and after the programme were described, analysed and the significance levels were calculated.

All interviews were audio-recorded and transcribed verbatim by the lead researcher (HW). The transcripts were not given to the participants to check for accuracy. Interviews were read and re-read by members of the research team (HW, SS, DB, CR) and were analysed using the Braun and Clarke method (Braun and Clarke 2006). Inductive coding was undertaken and common threads were identified from the grouped phrases independently. When this was complete the research team reviewed the codes to identify themes and through an iterative process came to agreement on the themes and sub-themes, ensuring credibility and transparency.

## Ethical considerations

Ethical approvals were obtained from the sponsoring university, one community NHS Trust acting as a participant identification centre and the Hospice (charity registered) where the intervention was delivered. NHS Health Research Authority's National Research Ethics Committee approved the study, NRES number XXXXXX.

## **Findings:**

Twenty-nine information packs were sent with 15 participants responding (response rate of 51.7%). Reasons for non-response was not collected. The final sample size completing the programme was 12; six from the first cohort and six from the second completed the programme. Three participants did not complete the programme. One participant in cohort 1 died in week 5 of the programme from a malignancy not anticipated when the programme commenced, and two participants in cohort 2 left the programme. One participant wanted a higher impact exercise component and so did not want to continue, and the second participant withdrew consent with no reason given. Participant demographics are presented in Table 2.

### **Questionnaire findings:**

#### **MLwHFQ:**

There was an overall improvement in quality of life in 5 of the 6 participants in cohort 1, but only 2 (out of 6) participants in cohort 2. Of the specific dimensions within MLwHFQ physical quality of life improved in 58% of participants following the programme and 50% reported an improvement in their emotional quality of life.

Paired t-test analysis before and after the programme shows no significant difference was found (significance  $p = <0.05$ ) in overall quality of life ( $p= 0.180$ ) or with either physical ( $p=0.077$ ) or emotional ( $p=0.543$ ) dimensions of quality of life.

#### **Emotional Thermometer:**

Only 4/12 participants expressed an improvement in their emotional well-being following the programme, indicating the programme did not have a detrimental effect on the emotional thermometer results. However only one participant requested further support with their emotional well-being following the completion of programme.

#### **Foot in the Door**

Eight of the 12 participants felt they had an improved support network as well as an increase in knowledge of where to find information and support following the programme. However, only 6/12 felt they were more informed about future choices. Before the programme 7/12 participants did not feel anxious using the services of the hospice and this opinion did not alter on completion of the programme. Five participants felt differing degrees of anxiety or apprehension about coming to a hospice before the programme, but this reduced in all participants on completion of the programme.

Table 2: Participant demographic profile

Participant	Age (years)	Gender	Aetiology HF	NYHA Class	Co-morbidities	Device present	Dyspnoea present	Fatigue Present	Other symptoms
<b>Cohort 1</b>									
1	89	Male	ischemic	III	CRF, DM, CHB, AF	PPM	Yes	Yes	Oedema
2	91	Female	HT	III	AF	No	Yes	Yes	None
3	82	Male	HT, MR	III	Schizophrenia, AF	No	Yes	Yes	Oedema, syncope, dizziness
4	82	Male	HT	III	COPD, AF	No	Yes	Yes	Cough, Oedema
5	88	Male	Ischemic	III	COPD, Anaemia	No	Yes	Yes	dizziness
6	88	Male	HT	III	Ca, CRF, enlarged prostate	No	Yes	Yes	Cough
7	Died								
<b>Cohort 2</b>									
1	89	Female	Ischaemic	III	PHT, DM, CA	No	Yes	Yes	Oedema, cough
2	74	Male	Ischaemic	III	Myelodysplasia	CRT-D	Yes	Yes	Dizziness
3	Withdrew								
4	81	Male	Ischaemic	III	DM, CKD, asthma	No	Yes	Yes	Cough, dizziness
5	68	Male	ACM	III	COPD, CKD, PHT, AAA, CVA, MR, enlarged prostate	No	Yes	Yes	Cough, dizziness
6	84	Female	Ischaemic	III	Ca, HT, CKD, OA, DM, CVA, hypothyroidism	No	Yes	Yes	Cough
7	Withdrew								
8	84	Male	ICM	III	None	CRT-D	Yes	Yes	None

*NB: Aetiology: HT= hypertension; MR = mitral regurgitation: Co-morbidity: CRF = chronic renal failure; DM = diabetes mellitus; AF = atrial fibrillation; CHB = complete heart block; COPD = chronic obstructive pulmonary disease, Ca = cancer. Device: PPM= Permanent pacemaker; CKD = chronic kidney disease; PHT = Pulmonary hypertension; AAA = abdominal aortic aneurysm; CVA = cerebral vascular accident; OA= osteoarthritis. Device: CRT-D = cardiac Resynchronisation Therapy with defibrillator; PPM = permanent pacemaker*

## Interview Findings

Table 3 presents the themes, sub-themes and codes from the inductive analysis. Four key themes emerged from our qualitative analysis: *demystifying perceptions about hospice; positivity about well-being; learning together and consideration of end of life preparation.*

Table 3: Themes, sub-themes and codes from thematic analysis

Theme	Sub-theme	Code
Demystifying perceptions about hospice	Hospice ambience	Transport, staff, restful, calm, helpful, contacts, resources, atmosphere, one to one, enjoyable
	The support offered by the hospice	
Positivity about well-being	Sharing of the heart failure experience	Company, meeting others, enjoyable, people, listened to, looked forward to, loneliness, happy, friendships, pleased to come, got me out, feeling better, confidence
	Realising an immediate purpose to life.	
Learning together		Interaction, know my limitations, interesting, enjoyable, listening, exercise good, good sessions, good structure, length of talks right, wanted more, not all useful, emphasised needed to know, learning, informative
Consideration of end of life preparation	Focused thoughts on practicalities	Useful, knew already, focussed mind, end of life reality, pragmatic approach, sensible, realisation, don't want to know, reinforced, depressing, don't want to think
	Confronting reality	

*Theme 1: Demystifying perceptions about hospice*

All participants discussed visiting the hospice and how different their view of hospice care was now they had been exposed to it. Two distinct sub-themes related to this demystifying included the *hospice ambience* and *the support offered by the hospice.*

Hospice Ambience:

All participants commented on the atmosphere of the hospice. They felt it was peaceful and had an immediate calmness when they entered. They enjoyed the environment created within the hospice, particularly enjoying the décor and brightness of the day hospice and the gardens which they were encouraged to sit in and enjoy.

*I thought it was absolutely wonderful and I mean all the feedback that I was getting from other people, well I found it impressive. (Cohort 2, participant 8).*

Five participants discussed how their perception of the hospice was very different to the reality.

*When I heard the first mention of the hospice I was frightened, because I thought, oh dear, that's coming up to the end, you know. But then when you get there, it is totally different.*

(Cohort 2, participant 6)

Support offered by the hospice:

All participants commented on the helpfulness of the hospice staff and how they were made to feel calm, with one participant previously feeling '*on the edge*'. Resources offered by the hospice were unknown to 11/12 participants with all unaware of future opportunities offered by the day hospice for people with heart failure.

*[the nurse] put over the various benefits that we got from the hospice very well. (cohort 1, participant 6).*

Theme 2: Positivity about well-being

Participants openly discussed the positive interactions of the course. Two distinct sub-themes related to the positivity including the *sharing of the heart failure experience* and *realising an immediate purpose to life*.

Sharing of the heart failure experience:

All 12 participants discussed how being with other people with heart failure was a positive experience. They described how they had previously felt isolated, but sharing experiences or just talking to others with the same symptoms and problems was good for them. They all felt a strong connection with each other which developed during the programme.

*I have no quarrel with it at all.. oh no, no, no, I think it's helpful to have other people about who've suffered in the same way (Cohort 1, participant 1)*

Realising an immediate purpose to life:

All participants talked about the wider context of the programme. One participant talked about how they had grown in confidence. Nine of the 12 participants commented on their initial experiences of loneliness and that although people visited or they lived with their partner, they often felt isolated and alone. They saw the programme as a social outing, as a day out and now that it had finished they felt lost.

*It was good to get out, yes, [give you purpose] yes and something to look forward to. That's it. I said to her [wife], what am I going to do Friday? I've got to go.... (Cohort 2, participant 5)*

Theme three: Learning together

Eleven of the 12 participants enjoyed the structure and learning in a group setting, feeling supported by fellow participants. Two participants found the length of the programme (2 hours per week for 8 weeks) not long enough often feeling the sessions were rushed, yet others (10/12) felt the length of the programme was just right. Seven of the 12 participants felt the intensity and pace were just right, yet others (3/12) found it either too difficult and did not want to participate or too easy (2/12) and wanted more. The programme appeared beneficial for those that might not have completed cardiac rehabilitation and a useful reminder for those who had (4/12).

*A lot of the information on what you should be doing and things like that, we knew already. So that was, well second hand to me a bit. (Cohort 2, participant 4)*

Others (5/12) felt going over things was useful and no session should be omitted.

*I thought it was good, because it brought up, I got information that I needed, that I had most of it already well it just emphasised it.....I think they are all needed as a reinforcement of what I know and was happening actually. (Cohort 1, participant 2).*

Theme four: Consideration of end of life preparation:

All participants discussed end of life issues, with all participants discussing either the taught session on advance care planning or that delivery in a hospice made them think about their own future and mortality. Two distinct sub-themes related to end of life including *focused thoughts on practicalities* and *confronting reality*.

Focused thoughts on practicalities:

The hospice environment was seen by many (11/12) participants as a favourable alternative to dying in hospital, and they were no longer worried or frightened by the hospice. The session on advance care planning focused a number of participants' (9/12) minds to what preparations might be required having not written a Will or thought through the practicalities.

One participant commented:

*I think people should be told, especially people I mean they're all there because they have a major, major problem, .... But you're not there for fun and I would have thought any information that would help, you know, it's got to be good, I would have thought. (Cohort 2, participant 4).*

Confronting reality:

Some participants (7/12) did not feel ready to have the conversation about dying and the end of their life. They did not want to plan for the future and were not ready to make decisions. Other participants (5/12) were very aware of their mortality and had thought through dying. One participant said:

*The end results of all of these [ailments] is exactly the same, at the end of the day, which in fact is, you're really not terribly well, chances are you're not really, you want to kid yourself that you're going to suddenly jump up and down you see, I'm guessing it isn't going to*

*happen. So from that point of view, that was good [the session]. I didn't find it depressing.*

(Cohort 2, participant 8)

## **Discussion**

Our adapted cardiac rehabilitation programme shows the potential to be an additional model for integrated specialist palliative care services for people with heart failure. The delivery of the programme in the hospice environment enabled participants to engage with palliative care services while at the same time explore the services offered by a hospice to support end of life care. Visiting on a weekly basis enabled participants to acquire their own experience of hospice and demystify some preconceptions, including the environment itself, the staff and the services that were available.

Participants reported positive experiences of the hospice from a perspective of the ambience of the environment and the support offered, as well as a changing of their preconceived ideas of what a hospice was. Five of the participants were anxious attending the hospice before the programme, yet all felt comfortable attending at the end. There was a considerable change in their views of what a hospice was and what support was offered. Our approach was specifically related to day hospice services. Metzger et al (2014) in their study exploring patient and family members views of hospice care in late-stage heart failure found participants described the hospice as having 'rules' which they had to abide by and this often put people off exploring a hospice as an option for end of life care. However, what does need to be acknowledged is this study was conducted in the United States of America where the funding model for hospice care differs to that in the UK. We found introducing participants in our study to the hospice environment earlier, the possibility for hospice support for either day or inpatient services were welcomed.

Palliative care is frequently viewed as a treatment of last resort and that transitioning to Hospice care requires accepting one is imminently dying (El-Jawahri et al., 2017). These notions of hopelessness and dependence have a powerful stigmatising effect (Zimmerman et al., 2016) which impacts on care decision-making and service utilisation (El-Jawahri et al., 2017). There is a concern

that patients and family members see palliative care and hospices as the same and are therefore resistant to engaging with palliative care for the fear of the realisation that they are about to die (Metzger et al 2014). This may have been why participants who were NYHA class IV chose not to participate in the programme.

Social isolation, actual or perceived has a significant negative impact on the quality of life of people with HF and increases both mortality and the use of healthcare services (Paturzo et al., 2016; Manemann et al., 2018). The evaluation of this programme shows opportunities to engage in social activity were positively perceived by people who often find that their world 'shrinks' as a result of their diagnosis.

Standard cardiac rehabilitation programmes are designed to promote self-management, with patients learning to monitor and respond to their own symptoms as well as the adherence with treatment provided by experts (Lainscak et al., 2011). This programme sought to also address emotional and psychological dimensions of care (Bradley et al., 2018), similar to typical palliative care Day Services provision. These elements may be overlooked at earlier points in the HF journey when emphasis is placed on disease modifying treatments rather than symptom management and the impact on quality of life (Hanratty et al., 2002). Of concern is that the programme identified that emotional support was lacking for HF patients and that even though they may live with family members they still felt alone and unaware of where to go for help and support.

Attendance on the course provided a valuable opportunity for participants, through engagement with others in similar circumstances, to establish a sense of camaraderie and social support. There is clear evidence that social support, both instrumental and emotional, plays an important and positive role in self-management (Fivecoat et al., 2018). Participants in this programme valued both the content of the sessions and the interaction with each other and professionals. Sharing with others also 'living with' heart failure enabled the exchange of information and a sense of validation.

Crucially, it also provided some with a sense of focus, purpose and control, the loss of which are commonly experienced consequences of HF (Jeon et al., 2010). Interestingly, although participants enjoyed the programme, there was no consensus over the content or structure suggesting it was the social aspect that was potentially the most beneficial.

One particular element of the content about which there was divergence was advance care planning. Advance care planning conversations have been shown to reduce hospitalisation when conducted as part of specialist palliative care input for patients with advanced HF (Evangelista et al., 2012; Kernick et al., 2018). These should be initiated early in the trajectory and reviewed regularly (Ahluwalia and Enguidanos, 2015; Howlett et al., 2010). The programme was conducted in an environment where professionals enabled participants to normalise the conversation. Sharing experiences with others prompted participants to consider the realities of their own situation and begin to address the practicalities of their future care in a more informal manner. Doukas and Hardwig (2003) suggest that informal conversations with significant others and care providers are the most critical component of end-of-life planning. This programme afforded individuals the opportunity to discuss their futures in an atmosphere of pragmatism in the face of uncertainty.

**Limitations:**

The study sample was small and therefore might have influenced the participants' experiences. This was mitigated by running two cohorts to ensure it wasn't related to group dynamics of one cohort. All participants of the study were from a white, Caucasian ethnic group and so members of the BAME (Black, Asian and Minority Ethnic) community are not represented in the study. Previous work by Dixon et al., 2015 suggests BAME groups were less likely to engage with hospice and palliative care services, a barrier that any developing service needs to overcome. The majority of participants were men, which is an international trend within general cardiac rehabilitation programmes, all were diagnosed with HFrEF, and NYHA class III.

The sampling strategy of the study is a limitation. Patients who participated did so in the knowledge the programme would be delivered in a hospice setting. It is not clear if those who were invited but declined did so because of the venue or their pre-existing knowledge and understanding or who felt they did not want to discuss end of life issues. Therefore the positive view of day hospice may have been biased with the self-selection of participants. Furthermore, the study was from one geographical area in England. Despite these limitations, the transferability of this study needs to be evaluated in light of the richness of the data. Detailed interviews at the conclusion of the programme reveal evaluative comments about the structure, location and timing that have subsequently been used to inform further iterations in other local settings.

#### **Implications for nursing and recommendations:**

A structured and integrated programme with heart failure and palliative care teams such as that reported here, may improve the experiences and understandings of people with heart failure. People with heart failure can benefit from interaction with others in a similar position, reducing feelings of isolation, and realising an immediate purpose to life; the hospice environment, although daunting at first can provide the ideal calm and supportive environment for this. Preparation for, and discussion of, end of life is needed in the heart failure trajectory but may be difficult for some to engage in; for many, such discussions focus thoughts on practicalities and allowed a supported confrontation of reality.

#### **Conclusion:**

This programme provided an additional model for integration of palliative care for people living with HF. Delivered in a Hospice environment, it provided an opportunity for patients to experience palliative care principles in action and demystify perceptions. The content and format promoted both self-management and social support, and created a forum for advance care discussions. The study did appear to show benefits to the participants, however these results need to be taken in the context of a small sample size and one geographical area. What is evident is the study was able to

show there is scope to develop programmes for people living with HF which advocate early integration of palliative care services

### References:

Ahluwalia, SC & Enguidanos S (2015) Advance care planning among patients with heart failure: A review of challenges and approaches to better communication. *Journal of Clinical Outcomes Management*. **22**. 73-82.

Austin J, Williams R, Ross L, Moseby L, Hutchinson S (2005) Randomised controlled trial of cardiac rehabilitation of elderly patients with heart failure. *European Journal of Heart Failure*; **7**(3):411-17.

British Association for Cardiovascular Prevention and Rehabilitation (2012) *The BACPR Standards and Core components for Cardiovascular Prevention and Rehabilitation 2012 (2<sup>nd</sup> Edition)*. British Cardiovascular Society, London

Bradley N, Lloyd-Williams M & Dowrick C (2018) Effectiveness of palliative care interventions offering social support to people with life-limiting illness-A systematic review. *European Journal of Cancer Care (Engl)*. May; **27**(3):e12837. doi: 10.1111/ecc.12837. Epub 2018 Mar 24.

Braun, V. & Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, **3**(2):77-101.

Butrous and Hummel (2016) 'Heart failure in older adults' in *Canadian Journal of Cardiology*; **32**:1140-1147.

Cheang MH, Rose G, Cheung CC, Thomas M. Current challenges in palliative care provision for heart failure in the UK: a survey on the perspectives of palliative care professionals. *Open Heart*; **2**:e000188. doi:10.1136/openhrt-2014-000188 pmid:25628893.

Devi, A. (2011) 'A timely referral to palliative care team improves quality of life' in *Indian Journal of Palliative Care*; **17**:14-16.

Dixon J, King D, Matosevic T, Clark M, Knapp M (2015) *Equity in the Provision of Palliative Care in the UK: Review of Evidence*. Personal Social Services Research Unit, London School of Economics and Political Science, London

Doukas DJ & Hardwig J (2003) Using the family covenant in planning end-of-life care: Obligations and promises of patients, families, and physicians. *Journal of American Geriatrics Society*, **51**, 1155–58.

El-Jawahri A, Traeger L, Shin JA, Knight H, Mirabeau-Beale K, Fishbein J, Vandusen HH, Jackson VA, Volandes AE, Temel JS (2017) Qualitative Study of Patients' and Caregivers' Perceptions and Information Preferences About Hospice. *Journal of Palliative Medicine*;20(7):759-766.

Evangelista, L.S., Lombardo, D.M., Malik, S., Ballard-Hernandez, J., Motie, M., & Liao, S.S. (2012). Examining the effects of an outpatient palliative care consultation on symptom burden, depression, and quality of life in patients with symptomatic heart failure. *Journal of Cardiac Failure*, 18(12), 894-9.

Ezekowitz J, O'Meara J, McDonald M, Abrams H, Chan M, Ducharme A, Giannetti N, Grzeslo A, Hamilton P, Heckman G, Howlett J, Koshman S, Lepage S, McKelvie R, Moe G, Rajda M, Swiggum E, Virani S, Zieroth S. (2017) Comprehensive Update of the Canadian Cardiovascular Society Guidelines for the Management of Heart Failure. *Canadian Journal of Cardiology*;33:1342-1433.

Fivecoat HC, Sayers SL & Riegel B (2018) Social support predicts self-care confidence in patients with heart failure. *European Journal of Cardiovascular Nursing*;17:598–604.

Gessier S, Low J, Daniells E, Williams R, Brough V, Tookman A, Jones L (2008) Screening for distress in cancer patients: is the distress thermometer a valid measure in the UK and does it measure change over time? A prospective validation study. *Psycho-Oncology*;17:6,538-47

Hanratty B, Hibbert D, Mair F, May C, Ward C, Capewell S, Litva A and Corcoran G. (2002) Doctors' perceptions of palliative care for heart failure: focus group study. *British Medical Journal*;325:581–5.

Howlett J, Morin L, Fortin M, Heckman G, Strachan PH, Suskin N, Shamian J, Lewanczuk R, Aurthur HM. (2010) End-of-life planning in heart failure: it should be the end of the beginning. *Canadian Journal of Cardiology*;26:135-41.

Jaarsma T, Beattie JM, Ryder M, McDonagh T, Mohacsi P, Murray SA, Grodzicki T, Bergh I, Metra M, Ekman I, Angermann C, Leventhal M, Pitsis A, Anker SD, Gavazzi A, Ponikowski, Dickstein, K, Delacretaz E, Blue L, Strasser F and McMurray J on behalf of the Advanced Heart Failure Study Group of the HFA of the ESC (2009) 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*;11;5, 433-43.

Jeon YH, Kraus SG, Jowsey T & Glasgow NJ. (2010) The experience of living with chronic heart failure: a narrative review of qualitative studies. *BMC Health Service Research*;10:77:Mar 24. doi:10.1186/1472-6963-10-77.

Johnson M, Nunn A, Hawkes T, Stockdale S, Daley A (2012) Planning for end-of-life care in heart failure: experience of two integrated cardiology-palliative care teams *British Journal of Cardiology*; 19:71-5.

Kavalieratos D, Gelfman LP, Tycon LE, Riegel B, Bekelman DB, Ikejiani DZ, Goldstein N, Kimmel SE, Bakitas MA, Arnold RM. (2017) Palliative Care in Heart Failure: Rationale, Evidence and Future Priorities. *Journal of the American College of Cardiology*;70:1919-30.

Kernick, L. A., Hogg, K. J., Millerick, Y., Murtagh, F. E. M., Djahit, A., & Johnson, M. (2018). Does advance care planning in addition to usual care reduce hospitalisation for patients with advanced heart failure: A systematic review and narrative synthesis. *Palliative Medicine*, 32(10), 1539–1551.

Lainscak M, Blue L, Clark AL, Dahlström U, Dickstein K, Ekman I, McDonagh T, McMurray JJ, Ryder M, Stewart S, Strömberg A & Jaarsma T (2011) Self-care management of heart failure: practical recommendations from the Patient Care Committee of the Heart Failure Association of the European Society of Cardiology. *European Journal of Heart Failure*;13: 115-126.

MacIver J and Ross H. (2018) A palliative approach to heart failure end-of-life care. *Curr Opin Cardiol*;33:202-207.

Manemann, SM, Chamberlain AM, Roger VL, Griffin JM, Boyd CM, Cudjoe TKM, Jensen D, Weston SA, Fabbri M, Jiang R, & Finney Rutten LJ (2018) Perceived Social Isolation and Outcomes in Patients With Heart Failure. *Journal of the American Heart Association: Cardiovascular and Cerebrovascular Disease*; 7: e008069. <http://doi.org/10.1161/JAHA.117.008069>

McIlvennan, C., Allen, L. (2016) 'Palliative care in patients with heart failure'. *British Medical Journal*;352:i1010 doi: 10.1136/bmj.i1010,

Metzger M, Norton S, Quinn J, Gramling R. (2013) “That Don’t Work for Me”: Patients and Family Members’ Perspectives on Palliative Care and Hospice in Late-Stage Heart Failure. *J Hosp Palliat Nurs*;15:177-182.

NICE (2018) *Chronic heart failure in adults*. Available at: <https://www.nice.org.uk/guidance/qs9> (accessed 23/12/19)

NICOR (2018) *National heart failure audit: 2016/17 summary report*. Available at: <https://www.nicor.org.uk/wp-content/uploads/2018/11/Heart-Failure-Summary-Report-2016-17.pdf> (accessed 23/12/19)

Pattenden JF, Mason AR and Lewin RJ. Collaborative palliative care for advanced heart failure: outcomes and costs from the ‘Better Together’ pilot study. *BMJ Support Palliat Care* 2013; 3(1): 69–76.

Paturzo M, Petruzzo A, Bertò L, Mottola A, Cohen MZ, Alvaro R & Vellone E (2016) The lived experience of adults with heart failure: a phenomenological study. *Annali Di Igiene: Medicina Preventiva E Di Comunita*;28:263–273.

Rector TS, Kubo SH, Cohn JN (1993) Validity of the Minnesota living with heart failure questionnaire as a measure of therapeutic response to enalapril or placebo. *American Journal of Cardiology*;71:1106– 7.

Rogers J, Patel C, Mentz R, Granger B, Steinhauser K, Fiuzat M, Adams P, Speck A, Johnson K, Krishnamoorthy A, Yang H, Anstrom K, Dodson G, Taylor D, Kirchner J, Mark D, O’Connor C, Tulskey J. (2017) Palliative Care in Heart Failure: The PAL-HF Randomized, Controlled Clinical Trial. *Journal of American College of Cardiology*;70: 331-341.

Stananought N, Greene M, Sutehrland J, Midgley C, Asiam E (2011) ‘A foot in the door’ – an introductory programme for patients with early stage motor neuron disease. *British Medical Journal Supportive and Palliative Care*;1,238

Wiskar K , Toma M , Rush, T (2018) Palliative care in heart failure. *Trends in Cardiovascular Medicine*;28:445-450.

World Health Organization (2014). Strengthening of palliative care as a component of comprehensive care throughout the life course.

At [http://apps.who.int/gb/ebwha/pdf\\_files/WHA67/A67\\_R19-en.pdf](http://apps.who.int/gb/ebwha/pdf_files/WHA67/A67_R19-en.pdf) (accessed 23/12/2019.)

World Health Organisation (2019) Definition of Palliative Care at

<https://www.who.int/cancer/palliative/definition/en/> (accessed 23/12/2019.)

Yancy C, Jessup C, Bozkurt B, Butler J, Casey D, Drazner M, Fonarow G, Geraci S, Horwich T, Januzzi J, Johnson M, Kasper E, Levy W, Masoudi F, McBride P, McMurray J, Mitchell J, Peterson P, Riegel B, Sam F, Stevenson L, Tang W, Tsai E, Wilkoff B. (2013) 2013 ACCF/AHA Guideline for the Management of Heart Failure: Executive Summary. *Circulation*; **128**:e240–e327

Zimmermann C, Swami N, Krzyzanowska M, Leighl N, Rydall A, Rodin G, Tannock I, Hannon B. (2016) Perceptions of palliative care among patients with advanced cancer and their caregivers. *Canadian Medical Association Journal*; **188**(10):E217-E227. doi: 10.1503/cmaj.151171.