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Living Well with Heart Failure – evaluating an education and support programme for patients and caregivers living with Advanced Heart Failure

Abstract

Background

The increase in Heart Failure incidence globally poses a major public health challenge. Living with advanced heart failure places a considerable burden on patients and their informal caregivers. Improved education and support to patients and their informal caregivers and input of palliative care services could support both in living with heart failure.

Aims and objectives

To evaluate an 8-week programme of education and support delivered in a day hospice for people diagnosed with heart failure and their informal caregivers.

Methods

Semi-structured focus groups were conducted. Patients and informal caregivers focus groups were conducted separately at the conclusion of the 8 week programme. They were recorded, transcribed verbatim and inductive thematic analyses were performed.

Results

A total of 10 focus groups were conducted. Most patient participants were male (92%), aged > 70 years, and most informal caregiver participants were female (93%) and aged > 50 years. Analysis of the data found the patient participants' themes

were the *Importance of Knowledge; Support and Communication; Gateway to Resources* and *'Living well' with heart failure*. The informal caregiver focus groups found similar themes; *Becoming Stronger; Altered Outcome for the Future and Connection through knowledge*.

Conclusions

Patients evaluated the 8-week programme positively, finding the increase in knowledge of heart failure and resources available increased their confidence and thoughts about their future. The support gained from other people with heart failure was invaluable. Informal caregivers through increased understanding of heart failure and access to peer support, reported feeling calmer, more confident and less fearful of what lay ahead.

Keywords Heart failure, palliative care, informal caregivers, patient education, peer support

Key points

Heart failure education and support is valuable for both patients and caregivers.

Increased knowledge of heart failure increases expressed confidence in its management.

Hospices may provide a suitable environment for support and education programmes.

Reflective Questions

How frequently do you care for people with heart failure and how confident are you in your own understanding of the condition?

To what extent are informal caregivers included in the care you provide on a daily basis?

How comfortable are you in identifying and providing care for people where the focus is palliative rather than curative?

Introduction

Heart failure is a global public health challenge that impacts negatively on the lives of an estimated 26 million patients and their families/caregiver (Savarese & Lund 2017). Along with their families, people with advanced heart failure live with a condition that is progressive, unpredictable and life-limiting. While the year-on-year incidence may fluctuate, the burden of the disease is increasing. In the UK it is estimated approximately 920,000 people live with heart failure (Conrad et al. 2018) and more than 60,000 people die each year (Hospice UK 2017). Reported inpatient mortality rate for patients admitted to hospital with heart failure in England and Wales is 9.2% with an increased rate of 39% within 12 months for those who survived to discharge (NICOR 2022). This group of people are elderly (mean age of 77.8 years on first admission) and often have multiple morbidities with high symptom burden even at rest (Stockdill et al. 2019).

Over recent years, heart failure care has focused on improving symptom management and collaboration between heart failure and palliative care teams (Kavalieratos et al. 2017; Lewin & Schaefer 2017; Sobanski et al. 2020) with evidence suggesting positive outcomes for patients (Johnson et al. 2012; Talabani et al. 2017).

Patients living with heart failure are as likely as those with advanced cancer to experience distressing symptoms, and yet they account for only 4% of specialist palliative care workload in the UK (Hospice UK 2017). In Europe only 7% of heart failure patients, compared to >50% of cancer patients have their palliative care needs recognised and as few as <1% die in hospices with heart failure as their primary diagnosis (Sobanski et al. 2020).

This underuse of hospice care for people with Heart Failure is consistent across many high-income countries even where hospice and palliative care programmes are well developed. There appears to be a lack of understanding of the spectrum of palliative care services and what the palliative care needs of this patient group are. This results from unpredictable disease trajectories, difficulties with prognostication as well as discomfort with palliative care from cardiac specialists and lack of knowledge about heart failure for hospice staff (Cross et al. 2019).

This places a considerable physical and emotional burden on patients and their informal caregivers who are '*living with heart failure*' but lack the benefit of specialist palliative care input (Dionne-Odom et al. 2017). How patients with heart failure and their informal caregivers identify and manage symptoms is an important contribution to both patient and caregiver outcomes (Lee et al. 2017). Studies have identified the role of the patient-informal caregiver dyad is key in the management of heart failure, hospital admissions and quality of life (Lee et al. 2017; Hooker et al. 2018; Lyons et al. 2020).

The aim of this study was to evaluate a hospice-based programme of education and support for people diagnosed with heart failure and their informal caregivers. The programme was designed and delivered in the UK hospice by multi-professional clinical and education specialists in Heart Failure and Palliative Care.

Methods

This study employed an inductive qualitative approach informed by phenomenological principles with a focus on the direct experiences of patients and their caregivers. National ethical approval was obtained (17/SW/0267) and the study conformed to the principles outlined in the Declaration of Helsinki (World Medical Association, 2013). The study is reported here in line with the COREQ reporting guidelines (Tong et al. 2007)

Intervention

An 8-week support and education intervention programme for both patients and informal caregivers was developed to engage people at any stage of their heart failure journey. It was delivered in a day hospice environment on the site of a regional hospital that provides specialist palliative care to a mixed urban and rural community. It was designed to enable all participants to experience the education together and with space within the weekly schedule to explore areas separately, further acting as support provision for both patients and informal caregivers. The design was based upon pilot work conducted at another local hospice (Walthall et al. 2020) that was then developed further by specialist heart failure and palliative care staff to include informal caregivers using the pilot study evaluations.

The programme consisted of 8 weekly sessions each lasting three hours. It was delivered by specialist palliative care nursing staff, a Consultant Nurse in Heart

Failure, specialist Physiotherapy, Occupational, Art and Music Therapists and a lay expert with personal experience of caring for a relative with advanced heart failure. Each week's session consisted of informal introductions, followed by an hour-long education presentation delivered by different members of the team. After a short break, patients and family caregivers split into separate groups. The patients engaged in a physical exercise activity led by specialist therapists. These low-impact activities were designed to accommodate the abilities of all participants so everyone could participate. At the same time, the family caregivers engaged in a group discussion session facilitated by the lay expert covering shared experiences and ways of managing daily life. The week's session concluded with a relaxation activity, a general discussion and the opportunity to have any questions answered. The timetable is shown in Figure 1.

Participant Selection and Recruitment

The study employed a purposive sampling approach. The inclusion criteria required that participants had a confirmed diagnosis of heart failure and be able to engage (based on cognitive and language ability) with an education and support programme delivered in English. Potential participants were identified by specialist Heart Failure nurses working in both inpatient and community teams from an ongoing review of their caseloads. The research was discussed with potential participants and their contact details were forwarded to the Project manager if they were interested in taking part. Potential participants were then sent a research pack containing the programme and study information, a consent form and a reply slip. One follow-up contact was made with non-respondents. At the first session, each participant was met by a member of the research team to review the study details and gain informed consent.

Data Collection

At the completion of the programme, evaluations from both patients and informal caregivers were sought. Separate focus groups for patients and caregivers were conducted by two female and one male member of the research team as part of the final session. Those facilitating the focus groups had no input into programme delivery although they had previous clinical and research experience in cardiac and palliative care settings. The focus groups were conducted using a topic guide, (See Figure 2) developed from the pilot study (Walthall et al. 2020) and designed to elicit participants' views of the content and length of the programme; the suitability of using a hospice environment; the reported outcomes of the programme and their recommendations. Each lasted between 35 and 65 minutes and were recorded using a digital audio recorder.

Data Analysis

Audio recordings were transcribed and analysed using a six-stage thematic approach (Braun & Clarke 2006). This proceeded upon completion of the final focus groups to ensure the entire data set was considered. Transcripts were read and coded independently by three researchers. Inductive coding was undertaken and common threads were identified from the grouped phrases within the data. The researchers reviewed the 48 patient codes and 69 caregiver codes (See Tables 1 & 2) to identify provisional themes, then collectively reviewed these, and through an iterative process came to an agreement regarding the final themes and sub-themes. Data analysis meetings were also attended by the lay expert to enhance credibility, dependability and authenticity of the data interpretation.

Results

The programme was delivered five times between January 2018 and March 2019 to groups of between 8 and 12 people. Over the 18 months of the project, 137 patients and 138 caregivers were invited to attend the self-management programme. Of these, 24 patients and 15 caregivers agreed to participate giving an acceptance rate of 18% and 11% respectively. Not all patient participants had a caregiver whilst others felt that it was unnecessary for their caregiver to attend. Of the caregivers who did attend, 14 were spouse/partner and 1 was a daughter.

Ten focus groups were undertaken (5 patients and 5 informal caregivers). Not all of those who participated in the programme were involved in the focus groups as some missed the final session (n=16) and so the total number involved in the data collection was 23 (13 patients and 10 caregivers). All but two of those in the patient focus groups were male and white British while all but one of the participants in the caregiver group were female and white British. Twenty-one of the patients were in their 70's and 80's with two in their 50's and one in their 40's. The caregiver group participants tended to be slightly younger.

All participants reported having benefited from undertaking the programme but analysis of the data sought to establish in what ways they had benefited and how this might have differed between the two groups. While some personal preferences were reported, no aspects were deemed 'unnecessary'. The key themes and how they emerged from the qualitative analysis are presented in tables 1 & 2 along with the data codes. This paper presents the themes from both sets of collated focus group data.

Patients Focus Groups:

Importance of Knowledge

A clear message from participants was a thirst for knowledge, feeling they needed to know more about the heart failure journey including how and why they experienced typical symptoms. All the patient participants found the taught elements to be useful, gaining a lot of information and knowledge on a weekly basis. They valued learning and sharing details about the nature of heart failure, anticipatory symptoms and details about medication. They also enjoyed learning together and the sharing of experiences with other people with heart failure.

“I enjoyed it all.....but I think for us, it’s been really good having people around in the same situation as us....” (Patient Focus Group 1)

“ this certainly allays a lot of fears you know. And it’s just so good, it’s good for you to talk to other people in similar, with similar problems. And certainly, the knowledge of the people that are running the course is probably better than most of the GPs that you see.” (Patient Focus Group 3)

The importance of knowledge to understand and manage heart failure symptoms was clearly evident in the data. Experiences were understood anew in light of details about the nature and impact of heart failure.

Support and Communication

Participants openly discussed the importance of talking and sharing experiences. This peer support was seen as a significant benefit as participants could establish the degree of similarity and difference, but also felt a sense of freedom to put their experiences into words. They acknowledged the caregiver’s role in their journey and their specific needs. Furthermore, the separate sessions for caregivers and patients in the programme were seen as key by patients. They felt it was important for

caregivers to have an opportunity to talk with others who understood their circumstances.

“Well meeting other people as well. You always think it’s just you and it’s a bit like [name].... I was interested by talking to [name] I didn’t know that, you know, so it’s something I learnt.” (Patient Focus Group 2)

“She [Caregiver] was glad she came along and went through it with me as well like, you know, because there’s some things she has to help me with because I can’t do it myself now.” (Patient Focus Group5)

Gateway to Resources

Participants commented on the positive reality of the hospice environment and the additional support available to them. They expressed feeling comfortable and safe in the hospice and felt the programme offered an additional channel for accessing professional knowledge.

“ I think [the hospice]’s probably an excellent choice. The atmosphere of the place is calm, nothing, nobody rushes around here.” (Patient Focus Group 3)

While the general environment was positively evaluated, the practicality of accessing facilities on a hospital site was not without difficulties. Issues related to transport (provided where requested) and parking did affect the overall impression of the programme experience.

Some participants felt there was scope for more explicit psychological support in the form of counselling.

“ I feel that there’s a major bit lacking in counselling...it’s different when you have an illness, do you know what I mean? Maybe if there was a little bit

more group therapy, where we could talk about maybe how we feel.” (Patient Focus Group 2)

‘Living with’ Heart Failure

Participants were able to consider their own mortality and the realities of having advanced heart failure. They discussed feeling out of control, fearing for the future, and fear of dying, but could also see it was possible to live with heart failure and appreciate hope for the future.

*“I suppose the biggest thing that it’s done for me, is it’s told me what to watch for...I’ve been in denial for a long time, I still don’t believe it.... So that, so it [the programme] hasn’t altered my behaviour but it’s altered my thinking.”
(Patient Focus Group 1)*

There was a shift in focus during the programme from the past and their individual ‘heart failure journey’ to the future and possibilities. Participants felt the programme gave them a sense of acceptance informed by focusing on the future.

“I think it’s been brilliant....I’m going away knowing people with it are living happily and I can carry on, well hopefully carry on the same as they’ve been doing, with much more knowledge now.” (Patient Focus Group 4)

Caregivers Focus Groups:

Becoming Stronger

Caregivers described becoming mentally and emotionally stronger after attending the programme. They found it had helped them feel emotionally-supported and saw the benefits of talking things through with other caregivers. Participants

acknowledged the caregiver role was often taken on reluctantly and came with a sense of burden and apprehension. However, following the programme they felt more relaxed, had increased confidence in caring for someone with heart failure and recognised an overall improvement in their own well-being.

“I think a lot of us were very broken when we arrived at the beginning of the course and I think... we’re a lot stronger, that we have shared experiences and we can support each other. We’ve learnt, we’ve grown, we’ve become stronger, we’ve talked about things that we’ve internalised inside us, these big evil subjects we haven’t wanted to talk about” (Caregiver Focus Group 1)

“You only feel buoyed up when you’re here because you’re all like-minded, all in the same boat” (Caregiver Focus Group 2)

Caregivers valued having their contribution in the care of their loved one acknowledged. They reported receiving minimal support in this role and having contact with others experiencing similar challenges was seen as a positive way forward.

Altered Outcome for the Future

Caregivers felt the course enabled them to build support networks for both themselves and their loved ones. They felt more able to have open conversations with their loved ones, felt less afraid of the future, less fearful of death and less alone. Most caregivers noticed this led to improvements in relationships with their loved ones.

“We’re happier at home... we’re a tiny bit more relaxed. It’s improved home life, it’s like a little light’s gone on at home again” (Caregiver Focus Group1)

“For us, it was good to do it together...it came at the right time for us...we’d just kind of build ourselves back up” (Caregiver Focus Group 4)

Caregivers reported they were now able to engage in honest conversations. They reported they had overcome some of the preconceptions of the hospice and the environment provided a safe space to talk and this was continued at home.

Connection through Knowledge

Caregivers emphasised how a greater understanding of heart failure had improved their resilience and confidence. The programme had enabled them to increase their knowledge of the condition, better understand symptoms, learn new tips and help them cope better during times of uncertainty. The programme gave an opportunity to learn alongside their loved ones, to know what they were experiencing and why, which helped the caregivers in their role.

“It was really enlightening, especially the breathing it’s helped my husband a lot. You know, when [name]’s coming out of breath, I remind him, breathe, breathe, breathe, and it’s very, very useful to know these little tips because otherwise we wouldn’t have known” (Caregiver Focus Group 3)

“It’s complemented and underpinned a lot of things that are happening medically, and it’s sort of put it in context and helped you understand it a bit more” (Caregiver Focus Group 5)

Discussion

This study demonstrates the potential for a hospice-based education and support programme for those living with heart failure that includes both patients *and* their

caregivers. The findings of the study suggested all participants valued the increased level of knowledge related to the nature and impact of heart failure. Adequate and accurate knowledge is a necessary antecedent for effective self-care of long term conditions and especially among those living with heart failure (Riegel et al. 2011). However, there do remain considerable misconceptions about the disease trajectory, not least because of the connotations of 'failure' and imminent decline (Ivynian et al. 2019). Our study sought to evaluate the effects of a programme covering a range of topics focussed on *'learning about'* in order to *'live with'* Heart Failure and sought to address many of these misconceptions in group discussions. While we did not set out to measure the degree of knowledge acquisition, evidence suggests that disease-specific outpatient-based multidisciplinary programmes like ours can produce durable and more accurate knowledge that supports and educates Heart Failure patients (Róin et al. 2019).

As well as the patient participants, caregivers also reported the significance of increased knowledge of heart failure rather than simply becoming expert by experience (Noonan et al. 2018). This provides caregivers with a greater sense of confidence in how they could support their loved ones and has the potential to ameliorate their uncertainty. It was our experience that new knowledge acquired throughout the programme helped to provide explanations and connections between caregivers' experiences and how they supported their loved ones with heart failure. However, it is important to acknowledge that, in their journey to becoming more expert, caregivers are likely to require ongoing relationships with professionals and others in similar circumstances rather than through simple, standalone interventions.

Our evaluation sought to establish the extent to which the programme's format helped to address some of the unmet needs of patients and caregivers. Providing opportunities for education and support which involved both groups, as well as offering a safe space to discuss the unique experiences of their role and position proved very effective. Both groups appreciated the opportunity to verbalise their experiences to an audience who understood what this involved at a practical level. Fear, social isolation and a perceived loss of control are common among patients with heart failure (Bidwell et al. 2017), topics that were addressed as part of the programme and plenary discussions. Similarly, caregivers increasingly become isolated as their loved one's mobility, functional ability and confidence declines and their care responsibilities increase (Dionne-Odom et al. 2017). Support and education formats that encourage regular social contact may help to address these issues providing a forum for the establishment of emotional and social support that are positively associated with confidence, management and could help alleviate caregiver burden (Fivecoat et al. 2018). The transactional relationship between patient and caregiver and the impact this has on heart failure self-management and self-care suggests that clinicians should pay more attention to the experiences of the patient/caregiver dyad in the future (Kim et al. 2020).

While evaluating the programme, we wished to establish the suitability of a Hospice Day Services environment as a particular venue for such an initiative. Myths and preconceptions about Hospice abound (Davison et al. 2016; McIlfatrick et al. 2021) driven by a social stigma that referral to a hospice is an implicit statement of poor

prognosis. Recent evidence would suggest this acts as a powerful barrier to the utilisation of palliative care services (Shen & Wellman 2019) at a time when greater integration of specialist palliative care and heart failure teams is being recommended (Johnson 2018). Interestingly, there were no expressions of these concerns or anxieties from the research participants about the hospice which is on the site of a well-known local hospital. Rather, they saw the programme and the environment as a Gateway to Resources, providing access to knowledgeable specialists in a setting that promoted candid discussions about managing the future. The setting provided an opportunity for participants to engage with a hospice environment earlier in their disease trajectory, enabling staff to demystify some of the misconceptions with the hope that future contact would be more likely and less anxiety-provoking. The increasing demand for specialist palliative care input for those living with non-malignant long term conditions and the growth of dedicated palliative care units staffed by professionals with the necessary communication skills means greater potential for this type of initiative.

The data for this study were collected before the global COVID-19 pandemic and our findings need to be re-evaluated in light of how future education and support programmes may develop. There is already considerable growth in e-health initiatives, telemedicine consultations and the use of remote monitoring. While these home-based initiatives have a number of advantages, they limit the ability of patients with heart failure to receive support and companionship from others who have shared experiences. Many patients' early heart failure journeys are typified by hospital admission following an acute deterioration, discharge and clinic follow-up. This means the ideal location and timing for future planning conversations that are

'quiet, non-clinical [and] at a time when the patient is stable and well enough to participate' is often hard to achieve (Denvir et al. 2014, p2). The hospice environment has the potential to provide exactly this sort of environment as well as access to knowledgeable and experienced staff who are able to empower patients and their families. While the development of future initiatives will need to consider the risks of vulnerable people coming into close proximity with each other, the value of this for peer support must also be acknowledged.

With a greater understanding of integrated models of care and clearer policy around these, there is a need to change the ways in which patients who are living with heart failure, and their caregivers, are engaged (Jaarsma et al. 2009). We suggest there is a need to adopt a comprehensive model of care for heart failure that is responsive to the ongoing challenges of living with an unpredictable chronic illness (Hupcey et al. 2009) based on the principles of integration rather than a replacement (Gelfman et al. 2017) of clinical specialities. The Living Well with Heart Failure programme supplemented the existing care provided by a specialist cardiologist, heart failure nurse specialists and palliative care teams. It resulted in outcomes for patients and caregivers that focused on additional forms of knowledge and social support. As a model, the programme has the potential to form the basis for interventions targeted at people living with a variety of long term conditions, where enhancing education, support and future planning are particularly challenging.

This study has demonstrated the potential of a Hospice-based education and support programme to positively influence the experiences of both those living with

heart failure and their caregivers. It was provided by specialists in heart failure and palliative care working together to address the anticipated and evolving needs of participants. While the programme demonstrated significant potential, the interpretation of our findings must be considered in light of the limitations. Uptake rates were low (18% patients and 11% caregivers) and the reasons for this were not clear. Any further programme developments will require a better understanding of the factors that encourage or discourage participation. The patient participants were predominantly male, the caregiver participants were predominantly female and cultural diversity was limited. It is unclear what impact this lack of diversity had on the responses provided in the study, and whether a greater mix of male and female participants in the study may have elicited significantly different responses.

In summary, the programme addressed issues of education and support for patients and caregivers living with heart failure. Patients gained access to both professional knowledge and the experiences of others in similar circumstances which were positively evaluated and reported that the hospice environment offered a suitable venue. Informal caregivers reported feeling calmer and more confident and less fearful of what lay ahead due to an increased understanding of heart failure and access to peer support. The size of the study limits the extent to which these outcomes can be quantified, however, as a model for the development of increasingly integrated education and support for those with advanced long term conditions, the Living Well with Heart Failure programme shows considerable potential.

Acknowledgements

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Tables and Figures

Sessions	
Week 1	What is Heart Failure?
Week 2	Managing stress and anxiety
Week 3	Managing breathlessness
Week 4	Keeping moving
Week 5	Nutrition and wellbeing
Week 6	How well do you sleep?
Week 7	Living with uncertainty
Week 8	Wellbeing and on-going support

Figure 1: Living Well with Heart Failure programme topic structure

Focus Group Guide:

The facilitator will ask the participants to discuss their experiences of the 8-week programme of support and education for patients diagnosed with heart failure and their informal caregiver in a day hospice.

The topics of interest are:

- the content of the programme
- the length of the programme
- its delivery in a hospice environment
- how they felt they benefited from the programme
- how it could be improved
- whether or not they would recommend it to others and why
- whether or not the programme has altered how heart failure is now managed at home
- what was the legacy of this programme for you?

Figure 2: Focus group guide

Table 1. Summary of themes and subthemes - Patient focus groups

Patient themes	Sub-themes	Codes
Importance of Knowledge	<ul style="list-style-type: none"> Managing symptoms effectively Heart failure quest 	Learnt a lot, delivery, content, expectations, anticipatory symptom management, useful, course language, sharing of knowledge, heart failure knowledge, enjoyed exercises, learning style, desire for knowledge, less anxious, confident, lack of medication knowledge, thirst for knowledge, balance of information
Support and Communication	<ul style="list-style-type: none"> Importance of talking Acknowledging the caregiver's needs Sharing of experiences 	Peer support, express symptoms, communication caregiver and patient, partnership journey, separate sessions, ongoing peer support, group communication, meeting others, talking good, caregivers needs
Gateway to Resources	<ul style="list-style-type: none"> The environment Access to provision 	Additional support, organised, routine, loss of continuity, safety, comfortable, timing, lack of psychological support, length of course, practicalities of getting to course, positive reality of hospice, appreciation of professional knowledge
Living with Heart Failure	<ul style="list-style-type: none"> Acceptance of condition What does the future hold? 	Facing own mortality, self-management, acknowledgment of symptoms, loss of control, fearing of dying, future tense, future hope, heart failure journey, possible to live with, acceptance of realisation.

Table 2. Summary of themes and subthemes - Caregiver focus groups

Caregiver themes	Sub-themes	Codes
Becoming Stronger	<ul style="list-style-type: none"> Psychological support Support for symptom management Need for caregiver support 	Calmer, changed at home, more relaxed, signs to look for, carers learning from each other, same for all, less anxious, peer support, needed extra support, sharing of experiences, manage symptoms, burden of caregiver, reluctance of caregiver role, apprehension, importance of caregiver managing, support and focus, experienced caregiver, timing, caregiver sessions, improved relaxation, increased confidence, improved

		well-being, emotionally broken, sharing, emotionally stronger, mentally stronger, opening up, support, mental and physical well-being, managing situations
Altered Outcome for the Future	<ul style="list-style-type: none"> • Building support networks • Dynamics of personal relationships • Less fearful of heart failure journey 	Honest conversations, importance of communication, building trust, developing relationships, meet people, hospice environment, no network, no longer alone, staying in touch, post course provision, beginning to relax, less anxious, hospice peaceful, hospice misconceptions, talking things through, impact of the course, realisation of journey, lack of peer support reassurance, honest with each other, improved communication with each other, safe environment, patient contribution, less fearful of death
Connection through Knowledge	<ul style="list-style-type: none"> • Knowing about heart failure • Consequence of new knowledge 	Course structure, course content, length, knowledge of condition, knowledge of heart failure, coping better, clarity of condition, don't know, learning tips, terminology, understanding symptoms, patient contribution, delivery understandable, take away resources, confidence, relevance of content, shared with family, patient and carer learning together, group size, learnt new things.