Current challenges in palliative care provision for heart failure in the UK: a survey on the perspectives of palliative care professionals

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ABSTRACT

Objective: Palliative care (PC) in heart failure (HF) is beneficial and recommended in international HF guidelines. However, there is a perception that PC is underutilised in HF in the UK. This exploratory study aims to investigate, from a PC perspective, this perceived underutilisation and identify problems with current practice that may impact on the provision of PC in HF throughout the UK.

Methods: A prospective survey was electronically sent to PC doctors and nurses via the UK Association for Palliative Medicine and adult PC teams listed in the UK Hospice directory.

Results: We received 499 responses (42%—PC consultants). Although PC provision for patients with HF was widespread, burden on PC services was low (47% received less than 10 referrals annually). While PC was acknowledged to have a role in end-stage HF, there were differing views about the optimal model of care. Levels of interdisciplinary collaboration (58%) and mutual education (36%) were low. There were frequent reports that end-of-life matters were not addressed by cardiology prior to PC referral. Moreover, 24% of respondents experienced difficulties with implantable cardioverter defibrillator (ICD) deactivation.

Conclusions: Low HF referrals despite widespread availability of PC services and insufficient efforts by cardiology to address PC issues may contribute to the perception that PC is underutilised in HF. The challenges facing PC and HF identified here need to be further investigated and addressed. These findings will hopefully promote awareness of PC issues in HF and encourage debate on how to improve PC support for this population.

INTRODUCTION

Heart failure (HF) is highly prevalent in the UK. In 2011, there were approximately 200,000 cases. It is projected to increase with an ageing population. As in terminal cancers, HF has a heavy symptom burden and poor prognosis. Palliative care (PC) is defined as an approach that optimises quality of life (QOL) in life-threatening conditions. Prompt PC intervention alleviates symptoms and improves QOL in chronic disease and at end-of-life (EOL). In the UK, it is delivered in the hospital, community or hospice setting by PC specialists or other healthcare professionals such as general practitioners (GPs) and HF specialists with adequate PC training. PC for HF is recommended in the latest European Society of Cardiology (ESC) and the UK’s National Institute of Clinical Excellence HF guidelines.

Numerous studies have documented various difficulties with PC provision in HF. These are mostly single centre studies, conducted in different countries or confined to regions in the UK. It is not clear what
the most significant challenges associated with the provision of PC in HF throughout the UK are. There is also a perception that PC services are underutilised in HF compared with cancer services.5 12–14 Similarly, the nationwide significance of this problem and associated reasons are unknown.

This exploratory study aims to investigate the following questions from the perspective of the PC professional: (1) What are the reasons for the perceived underutilisation of PC services throughout the UK? (2) Are there any significant problems with current provision of PC for HF nationwide?

**METHODS**

We conducted a prospective survey of UK PC professionals. Four important themes were identified from the existing literature, ESC guidelines and the professional opinion of HF and PC members of this research group:

1. PC provision for HF services and the relative burden on PC resources;
2. Current practice and professional perception of the role of PC in HF;
3. PC challenges specific to HF: implantable cardioverter defibrillator (ICD) deactivation and EOL discussions;
4. Interdisciplinary collaboration (which refers to various working arrangements that exist between cardiology and PC).

The survey consisted of 21 questions (see online supplementary file): 18 multiple choice questions (MCQs) with the option of entering free text in 7 of the 18 MCQs, 2 number entry questions and a final one asking for ‘any other comments’ (free text entry). Completion took 10–15 min. To assess the relative burden of patients with HF on PC services, respondents were requested to provide the number of PC patients and patients with HF currently under their care and to estimate the number of HF referrals they received in the preceding year. ‘HF Burden’ was defined as the number of patients with HF as a main diagnosis expressed as a percentage of the total number of patients currently under their care. In five MCQs, more than one response was allowed (indicated by ‘tick all that apply’ instruction). Respondents had the option to skip any question. The survey also collected information relating to the ‘demographics’ of our respondent population, that is, respondent’s role (consultant or specialist nurse, etc.), geographical locality, PC setting (hospital, hospice or community) and type of PC service they provided.

A provisional questionnaire was developed by one of the authors and subsequently reviewed by a group of HF and PC professionals (consisting of 5 doctors and nurses from 2 different institutions). Their suggestions were discussed by the research team and changes to wording, structure and arrangement of questionnaire were implemented to optimise the face and content validity. The final version was assessed for reliability by five PC professionals. The results were discussed and a consensus was reached on the final changes to the survey. SurveyMonkey, a web-based service, was used to create an online self-administered survey.

Our target population included consultants, non-consultant doctors, specialist nurse practitioners and other nurses working in PC within the UK. In the covering letter, we explained the objective of the survey and requested that all members of our target population participate, even if they worked in the same PC service. They were also assured of anonymity and asked to fill in the survey just once. The survey was electronically sent out twice (3 months apart) to all members of the UK Association of Palliative Medicine. In addition, it was sent to all adult PC teams listed in the UK Hospice directory (http://www.hospiceuk.org) with the request that the recipient forward the email on to relevant team members. Our survey started in June 2013 and closed in December 2013. We received confirmation from the local ethics committee that ethics approval is not necessary for the conduct of this survey.

**Quantitative analysis**

The results were downloaded from SurveyMonkey onto an Excel spreadsheet format and exploratory data analysis was performed using Excel. Data were expressed as a median for continuous variables and frequencies for categorical data. As this study was designed to be exploratory, bivariate associations and inferential analysis were not undertaken.

**Qualitative analysis**

Free text was analysed by the framework approach.15 After familiarisation with the raw data, key themes were identified from the study objectives and issues raised by respondents. The raw data were organised according to the themes. Concepts and associations were highlighted and interpretations were subsequently made. The results were independently reviewed by each of the authors, discussed, and a conclusive interpretation was reached by consensus.

**RESULTS**

Eleven (2%) of the 510 responses did not belong to the target population and were excluded. Respondents were distributed throughout all 19 regions of the UK (figure 1). Consultants accounted for 42% of responses (28% clinical nurse specialists, 6% other PC nurses, 24% non-consultant doctors). Most were based mainly in a hospice (59% hospice, 46% hospital, 21% community) and 18% worked in more than one site.

**PC provision for HF and the burden on services**

Almost all respondents offered PC services to patients with HF (97%). A range of PC services (which included hospice inpatient, day hospice, community and home-care, and hospital inpatient and outpatient) could be...
found in all regions of the UK. The minority (2%) who
did not offer services for HF gave no reason, were based
in a cancer centre or mentioned having an alternative
service (eg, joint PC clinics for patients without cancer).

Forty-seven per cent reported receiving less than 10 or
no HF referrals in the preceding year while only 3%
received more than 50 referrals (figure 2). Fifty per cent
of participants were able to provide numbers of patients
with HF and PC patients currently under their care. This
cohort is well distributed throughout all regions of the
UK (figure 3). The median ‘HF burden’ was 3% of the
total PC workload. Fifty-eight per cent of this cohort
reported having a low HF burden (between 1% and
10%) while 27% reported having no patients with HF
currently under their care. Similarly, low referral
numbers were also reported in free text entries. Several
respondents suggested that this may be due to under-
recognition of PC needs by cardiologists, PC profes-
sionals and patients.

Current practice and professional perception of the role
of PC in HF
A minority of respondents (14%) had specific HF refer-
ral criteria (80% had no specific criteria and 6% ‘did
not know’). Table 1 lists criteria used by respondents.
Breathlessness management pathway, symptom control
guidelines and EOL pathways were commonly cited as
treatment guidelines in HF. Subcutaneous diuretic and
ICD deactivation guidelines were infrequently
mentioned.

Almost all respondents (99%) agreed that PC has a
role in the management of severe or end-stage HF. The
majority (more than 70%) felt that end-stage HF (indi-
cated by deterioration in symptoms, recurrent hospital
admissions and EOL) was the most appropriate time
for PC referral. Initial diagnosis or consideration of
advanced HF management (ie, cardiac resynchronisa-
tion therapy, ICD or heart transplant) was not frequently
cited as the ‘most appropriate time for referral’ (4% and
41%, respectively).

Table 2 outlines the main themes that arose from rele-
vant text responses. Despite unanimous agreement on
the need for PC involvement in end-stage HF, there was
a spectrum of views on the required level of involve-
ment, as seen in comments below.

“If community matrons are involved there is often
nothing additional for us to add until end of life,” and
“...we should be seeing/helping more patients with end
stage heart disease...”

Difficulties with ICD deactivation
Twenty-four per cent of respondents reported experiencing
difficulties with ICD deactivation at EOL. These
respondents were distributed in all regions of the UK (apart from North Scotland). Notably, some respondents who reported ‘no difficulties’ admitted having had no prior or minimal experience with management of ICDs. The main difficulties associated with ICD deactivation can be summarised by three dominant themes, as outlined in Table 3.

Figure 2  Reported number of heart failure (HF) referrals received in the previous year—according to locality.

Figure 3  Median burden of heart failure (HF) on palliative care (PC) services (burden expressed as the percentage of patients with HF to the total number of PC patients currently under their care).
Conversely, respondents in localities where an ICD deactivation policy had been set up reported significant improvements in service (particularly better timeliness and access to deactivation service or magnets during out-of-hours, in hospices or the community) and greater interdisciplinary cooperation.

Other PC challenges in cardiology
A large majority (83%) of respondents reported that issues surrounding ICD deactivation and EOL care were seldom or never discussed by cardiology before making a PC referral. This problem was seen in all regions of the UK. There was broad agreement that further improvements to PC support in HF were needed, particularly in the home or community setting (although there were reports of good community support provided by some HF nurses). Other difficulties unique to HF are tabulated in table 4. Examples of efforts to improve PC service include new staff recruitment, active research and creating new pathways, working arrangements or treatment guidelines.

Collaboration between cardiology and PC
Interdisciplinary collaboration could be found in all regions of the UK and in all three PC settings. However, only 58% of all respondents reported having some form of collaboration. This figure increased to 71% when consultant responses were analysed in isolation (figure 4). ‘Joint working’, which refers to informal ad hoc working arrangements based on need, was most common (71%). More formal organised collaborations such as preplanned multidisciplinary team meetings (37%), steering/working groups (21%) and mutual education organised between PC and HF (36%) were less frequently observed. Nevertheless, several comments

| Table 1 | Referral criteria currently used |
|---------|---------------------------------|
| Commonly cited |
| - Severity of HF |
| - Recurrent hospital admissions with decompensated HF |
| - Inappropriateness of further hospital admission |
| - When PC needs are not met by cardiology, including complex and persistent symptom control issues, psychosocial issues, EOL and ACP discussions |
| Less commonly cited |
| - Exclusion of reversible causes |
| - Criteria based on Gold Standards Framework21—particularly prognostic indicators |
| - Generic (rather than disease specific) PC criteria |

ACP, advance care planning; EOL, end-of-life; HF, heart failure; PC, palliative care.

| Table 2 | Role of PC in HF—main themes |
|---------|-------------------------------|
| Themes | Examples of comments |
| PC in HF has unique aspects (e.g., disease chronicity) | “The HF patients often have a very different journey from cancer patients…trends tend to be long standing and chronic” |
| Uncertainty about optimal timing for PC involvement due to unpredictable prognostication | “It can be very difficult to know when to become involved with this client group” |
| “Shared care” is preferred as HF team frequently continues involvement | “…treatment of the underlying condition remains important throughout; therefore the heart failure CNSs remaining involved is essential” |
| PC’s role is to “support” HF team in complex symptom management, ACP discussions and other issues related to EOL | “…role of palliative care teams…is supporting the cardiology teams to be more comfortable with complex communications especially around resuscitation, ACP, etc” |
| Some situations require PC teams to lead and initiate intervention | “Heart failure CNS(s) vary in their confidence to manage symptoms & discussions surrounding EOLC issues & we sometimes need to take a lead with this” |

ACP, advance care planning; CNS, Clinical Nurse Specialists; EOL, end-of-life; HF, heart failure; PC, palliative care.
reveal that informal working arrangements in a supportive environment can also be productive. Other examples of current collaborative models of care include joint (clinic/home) consultations, jointly organised patient support groups, HF rehabilitation programmes in hospices and assimilating PC professionals into HF teams.

Although there were some reports of good existing cooperation, several respondents expressed the desire to foster closer links with cardiology. There was recognition that close working relationships encouraged appropriate referrals and improved mutual education, patient outcomes and staff satisfaction.

DISCUSSIONS AND LIMITATIONS

Although this study involved many respondents widely distributed throughout the UK, as in all surveys, a degree of sampling bias is to be expected. First, most respondents were based in a hospital or hospice setting. Therefore, while it is fairly common for PC professionals in the UK to work in hospice and community, our findings do not adequately reflect the unique issues associated with community PC provision. Second, a limitation associated with our method of distribution is the fact that the survey responder rate (which is a conventional marker of sampling bias) could not be calculated. Nonetheless, we have estimated a consultant

| Table 3 Difficulties associated with implantable cardioverter defibrillator (ICD) deactivation—three main themes |
|--------------------------------------------------------|
| **Themes** | **Examples of comments** |
|--------------------------------------------------------|
| 1. *Reasons for limited access to ICD deactivation* | “Unable to deactivate out of hours” |
| | “No availability of staff or a magnet to deactivate out of hours in a community hospital” |
| Poor out-of-hours access | “Difficulty getting ICDs inactivated as outpatients or when hospice inpatient” |
| | “Patients in the community—Unable to access anyone to come out and deactivate in a dying patient” |
| Unavailable in the community | “Delays, particularly in the community setting” |
| or hospice | “Delays due to lack of defined process in the community” |
| Excessive time delays | “Unavailability of magnets for temporary deactivation” |
| | “Needed to obtain magnet from CCU out of hours in order to deactivate ICD” |
| Lack of access to magnets | “Confusion around size of magnet needed” |
| | “…difficult to arrange availability of magnet and to ensure education on how to use one” |
| Insufficient education on ICD deactivation | “Access to technician support in the community—organised eventually but took lots of phone calls” |
| | “No local policy to my knowledge” |
| | “Took time to make contacts to arrange deactivation of ICD. Would be good to have regional flow charts on procedure for deactivation and contact numbers” |
| Organisational difficulties | “Cardiology team reluctant to take the lead on decision-making” |
| | “Electrophysiology services unwilling to have conversations and make decisions (regarding) turning off ICDs” |
| Decision-making on ICD deactivation | “Not thought about early enough, unable to deactivate in time” |
| | “Lack of forward planning at times in the community” |
| | “Prior discussions on deactivation—that have not been had early enough” |
| Advance care planning: pre-empting ICD deactivation | “Problems more associated with difficult communication issues” |
| | “Medical team reluctant to discuss with patient” |
| | “Need to ensure discussion about deactivation occur at insertion” |
| | “These discussions take place at the point at which they are inserted but are usually forgotten by the time they come into focus” |
| Communication issues related to ICD deactivation | “Patients not knowing they will need to be deactivated” |
| 2. *Issues surrounding ICD deactivation that require improvement* | “Patient was against having ICD deactivated” |
| | “Patient was reluctant to the idea of turning the device off” |
| | “…patient did not want it deactivated but his family did” |
| 3. *Patient-related barriers to deactivation* | CCU, Coronary Care Unit. |

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survey responder rate of 42% from the 2012 Royal College of Physicians workforce census (210 consultant responses vs 502 known PC consultants in the UK).

It is worth noting that this exploratory study was mainly designed to identify reasons for the perceived underutilisation of PC services and to detect any problems currently associated with present practice. Conducting an accurate UK-wide census of PC services for HF was not our study’s objective. Hence, while our results may indicate availability of PC services, it should neither be interpreted as a definitive assessment of provision in HF nor as a proportional representation of the views of PC professionals. Furthermore, the strength of signal in the qualitative analyses was not determined given the exploratory design of this survey. The deliberate decision to principally target PC professionals in this exploratory survey is based on the recognition that they are more likely to recognise unaddressed PC needs in the HF population. Thus, our findings offer a PC’s perspective into the current challenges facing PC in HF.

This survey reveals that although a range of PC services for HF is offered throughout the UK, HF referral numbers (and consequently burden on PC services) remain low. In addition, two observations were noted: an impression that cardiologists were under-referring and reluctant to engage with PC. The frequency of these observations is undetermined. Low HF burden or referral numbers (and consequently burden on PC services) fluctuates with time. Moreover, reports of specialist PC

Table 4 Other difficulties unique to palliative care (PC) in heart failure (HF)

| Themes                                                                 | Examples of comments                                                                                     |
|------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------|
| Cardiologists are unfamiliar with identifying and managing              | “Advance care planning is the main challenge we have… cardiologists not sure when and how to do so”       |
| palliative needs of patients with HF                                    | “…reluctance to refer patients because discussions (regarding prognosis) have never happened…”           |
| Observations of reluctance by cardiologists to engage with PC          | “Some heart failure clinicians easier to engage than others”                                            |
| profession                                                              | “Having a cardiologist that ‘doesn’t do palliative’ can make it more difficult to give help/advice to both patients and other team members” |
| Observations of patient reluctance to engage with PC                   | “The main issue often…(is) prognostication and the patients’ perception of how ill they potentially are”   |
| profession for various reasons (eg, unaware of severity of their        | “…HF patients often have a very different journey from cancer patients and the stigma surrounding palliative care and cancer at times persists” |
| condition and stigma associated with use of PC)                        | “…we have not had success in persuading patients to have PC assessment”                               |
| Insufficient PC resources to cope with additional workload             | “…should be more involved with heart failure patients… the issue is how to do this most effectively with an already overstretched palliative care service… needs to be investment into palliative care services to provide this” |
| A need and desire by PC professionals to improve training in            | “Two of the greatest barriers to good care by palliative services for patients with heart failure is…the limited knowledge that palliative specialist doctors and nurses have into the current best management of heart failure (esp. cardiac drugs and interventions such as biventricular pacemakers) not just to prolong life but to best manage symptoms caused by fluid overload and weak cardiac function…” |
| relevant PC skills for cardiology and vice versa for PC                 | “…in my experience the reluctance (by the cardiology team) to provide this (PC) is… lack of knowledge in symptom control and complex communication but with support from palliative care teams and education this can be improved” |
|                                                                        | “General lack of confidence amongst PC CNSs around heart failure as opposed to malignancy”                 |

CNS, Clinical Nurse Specialists.

Cheang MH, Rose G, Cheung C-C, et al. Open Heart 2015;2:e000188. doi:10.1136/openhrt-2014-000188
providing a ‘supportive’ and advisory role also means some of the burden is shared between HF and PC teams. Despite that, the low referral numbers do appear to be at odds with high HF prevalence. Recurrent observations by PC professionals of reluctance or unfamiliarity within cardiology to engage with and address PC issues with patients (including opening EOL and ICD deactivation discussions) corresponds with the published literature. It is likely that these factors contribute to the perception of PC underutilisation in HF.

As terminal diseases often tend to have similar PC needs at EOL, it is unsurprising that the use of generic referral criteria and treatment guidelines is common practice. However, the significance of the infrequent use of HF-specific criteria and guidelines is unclear. In addition, 42% of respondents did not cite “consideration of advanced HF management” as “most appropriate time for referral” despite it being indicative of increasing symptom burden and PC need. Further investigation is needed to ascertain if these observations indicate insufficient effort by PC services to cater for disease-specific needs, unfamiliarity with disease trajectory or an alternative explanation. Indeed, the overall impression from this survey is that further improvement in PC support for patients with HF is needed in the UK. Nevertheless, the key question is whether PC needs in HF are currently inadequately addressed nationally. If so, this could be due to under-recognition of HF needs by both specialties.

Despite broad acknowledgement of the value of PC in end-stage severe HF, there was divergence in views on the level and timing of PC input. PC needs are often predicated on whether a patient is nearing EOL. Tools such as the Gold Standards Framework (GSF) Prognostic Indicator guidance and the Supportive and Palliative Care Indicator Tools (SPICT), have been developed through research and collaboration to help identify patients approaching EOL in order to meet clinical need. Indeed, the referral criteria cited by respondents are supported by the GSF and SPICT tools. However, the clinical trajectory in HF is inherently unpredictable. Given that predicting PC needs with clinical indicators is fraught with difficulties, professional uncertainty regarding the optimal time to initiate PC needs assessment and discussion is unsurprising. This has contributed to the growing opinion that a better option may be to introduce PC at an earlier stage to run in tandem with conventional HF treatment such that PC provision may be more responsive to the individuals’ fluctuating needs throughout the disease journey.

There were markedly different views among PC professionals on the optimal model of care to cope with ever increasing HF demand. It is certainly encouraging to see different interdisciplinary working arrangements evolving to suit the skills and enthusiasm of local teams and resource availability in order to meet local demand. However, more research into optimum models of PC delivery is warranted. The relatively low level of interdisciplinary collaboration reported by PC professionals is consistent with a 2004 survey conducted in England by Gibbs et al (58% in present study vs 59% in 2004). Furthermore, the disparity in reported levels of collaboration by consultants versus non-consultant staff may indicate less involvement of non-consultant staff in interdisciplinary cooperation and merits further exploration. Despite
that, services that made concerted interdisciplinary efforts to deal with all PC issues reported improved outcomes. This is in agreement with published evidence.5 9 There is certainly a need26 and desire among PC professionals (reflected in comments) to develop interdisciplinary education and improve mutual skills.

When managed poorly, ICD deactivation can cause significant distress to the patient and family.36 Disappointingly, the 24% who experienced ICD difficulties were distributed in nearly all regions of the UK. Moreover, this figure is probably an underestimate as low referral rates could be masking the true extent of the problem. It is worth noting that many of the listed factors contributing to ICD difficulties are related to poor service organisation. This problem is not unique to the UK, as suboptimal provision of ICD deactivation service in US hospices was also documented in 2010.27

In addition, observations of patient reluctance with deactivation and to engage with PC emphasises the importance of early initiation of frank PC discussions.

We have presented a UK-wide overview of significant challenges currently facing PC and HF from a PC perspective. This is also the first study, to our knowledge, to document the difficulties surrounding ICD deactivation throughout the UK. It is disappointing to find that difficulties still persist in PC provision for HF in 2014. We hope that our findings will reinvigorate the debate on PC in HF among cardiologists, particularly on the following issues: reassessment of contemporary PC needs as new HF therapies emerge, optimal timing for initiating PC discussions or needs assessment and ideal interdisciplinary working arrangements to deliver efficient care. The fact remains that cardiologists are often the gatekeepers to PC services for the patient with HF. Therefore, improvement of PC provision in HF must first start with raising awareness of its benefits among cardiologists and encouraging interdisciplinary dialogue.

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Data sharing statement All the data from this study are only available to the authors listed in this paper.

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REFERENCES

1. British Heart Foundation. Prevalence. http://www.bhf.org.uk/research/heart-disease-statistics/morbidity/prevalence.aspx (accessed 8 Apr 2014).

2. Blinderman CD, Homel P, Billings JA, et al. Symptom distress and quality of life in patients with advanced congestive heart failure. J Pain Symptom Manage 2008;35:594–603.

3. Solano JP, Gomes B, Higginson IJ. A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. J Pain Symptom Manage 2006;31:58–69.

4. NICOR. National Institute for Cardiovascular Outcomes Research. National clinical audit: Heart Failure Annual report 2012/13. https://www.ucl.ac.uk/nicor/audits/heartfailure/reports (accessed 8 Apr 2014).

5. O’Leary N. The comparative palliative care needs of those with heart failure and cancer patients. Eur J Palliat Care 2009;16:30–33.

6. Jaarsma T, Beattie JM, Ryder M, et al. Advanced Heart Failure Study Group of the HFA of the ESC. Palliative care in heart failure: a position statement from the palliative care workshop of the Heart Failure Association of the European Society of Cardiology. Eur J Heart Fail 2009;11:506–13.

7. Lorenz KA, Lynn J, Dy SM, et al. Evidence for improving palliative care at the end of life: a systematic review. Ann Intern Med 2008;148:147–59.

8. Gomes B, Calanzani N, Curiale V, et al. Effectiveness and cost-effectiveness of home palliative care services for adults with advanced illness and their caregivers. Cochrane Database Syst Rev 2013;6:CD007760.

9. Bailey FA, Burgio KL, Woody LL, et al. Improving processes of hospital care during the last hours of life. Arch Intern Med 2008;168:1722–7.

10. European Society of Cardiology. ESC Clinical Practice Guidelines: Acute and Chronic Heart Failure. http://www.escardio.org/guidelines-survey/esguidelines/Pages/acute-chronic-heart-failure.aspx (accessed 8 Apr 2014).

11. National Institute for Health and Care Excellence. Chronic heart failure: management of chronic heart failure in adults in primary and secondary care. http://www.nice.org.uk/guidance/cg108/resources/guidance-chronic-heart-failure-pdf (accessed 24 Jul 2014).

12. Gibbs LM, Khatri AK, Gibbs JS. Survey of specialist palliative care and heart failure: September 2004. Palliat Med 2006;20:603–9.

13. Anderson H, Ward C, Eardley A, et al. The concerns of patients under palliative care and a heart failure clinic are not being met. Palliat Med 2001;15:279–86.

14. Riegel B, Moser DK, Powe NR, et al. Nonpharmacologic care by heart failure experts. J Card Fail 2006;12:149–53.

15. Pope C, Ziebland S, Mays N. Qualitative research in health care. Analysing qualitative data. BMJ 2000;320:114–16.

16. Federation of Royal Colleges of Physicians’ annual census of consultant physicians and medical registrars in the UK 2012. https://www.rcplondon.ac.uk/resources/2012-census-summary (accessed 24 Jul 2014).

17. Oishi A, Murtagh FE. The challenges of uncertainty and interprofessional collaboration in palliative care for non-cancer patients in the community: a systematic review of views from patients, carers and healthcare professionals. Palliat Med 2014;28:1081–8.

18. O’Leary N, Tieman E. Survey of specialist palliative care services for noncancer patients in Ireland and perceived barriers. Palliat Med 2008;22:77–83.

19. Barclay S, Momen N, Case-Upton S, et al. End-of-life care conversations with heart failure patients: a systematic literature review and narrative synthesis. Br J Gen Pract 2011;61:e49–62.

20. Kavaleratos D, Mitchell EM, Carey TS, et al. “Not the ‘grim reaper service’”: an assessment of provider knowledge, attitudes, and perceptions regarding palliative care referral barriers in heart failure. J Am Heart Assoc 2014;3:e000544.

21. The Gold Standards Framework. Library, Tools & Resources—Prognostic Indicator Guidance. http://www.goldstandardsframework.org.uk/cd-content/uploads/files/General%20Files/Prognostic%20Indicator%20Guidance%20October%202011.pdf (accessed 8 Apr 2014).

22. Supportive and Palliative Care Indicators Tool (SPECT). http://www.spect.org.uk (accessed 8 Apr 2014).

23. Haga K, Murray S, Reid J, et al. Identifying community based chronic heart failure patients in the last year of life: a comparison of the Gold Standards Framework Prognostic Indicator Guide and the Seattle Heart Failure Model. Heart Fail J 2012;28:779–83.

24. Gadoud A, Jenkins SM, Hogg KJ. Palliative care for people with heart failure: summary of current evidence and future direction. Palliat Med 2013;27:822–8.

25. Green E, Gardiner C, Gott M, et al. Exploring the extent of communication surrounding transitions to palliative care in heart failure: the perspectives of health care professionals. J Palliat Care 2011;27:107–16.

26. Fromme EK, Stewart TL, Jeppesen M, et al. Adverse experiences with implantable defibrillators in Oregon hospices. Am J Hosp Palliat Care 2011;28:304–9.

27. Goldstein N, Carlson M, Livote E, et al. Brief communication: management of implantable cardioverter-defibrillators in hospice: a nationwide survey. Ann Intern Med 2010;152:296–9.
Survey of Specialist Palliative Care and Heart Failure

The findings of this survey will contribute to improving future collaboration between Palliative care and Heart failure services. It will take 5-10 minutes to complete. The results will be collated and anonymised. Thank you for your time.

1. What is your role within your specialist palliative team?

| Role                                      | Options            |
|-------------------------------------------|--------------------|
| Consultant                                | Specialist registrar|
| Clinical Nurse Specialist                 | Clinical Lead      |
| Other (please specify)                    |                    |

2. Where are you based?

| Area       | Options                                    |
|------------|--------------------------------------------|
| Hospice    | Community                                  |
| Hospital   | Other (please specify)                     |

3. Within which geographical region are you based?

| Region                                | Options                               |
|---------------------------------------|---------------------------------------|
| Northern Yorkshire and Humber         | North Western                         |
| East Midlands                         | East of England                       |
| Severn                                | Kent Surrey and Sussex                 |
| South West Peninsula                  | North Scotland                        |
| West Scotland                         | East Scotland                         |
| South East Scotland                   | North Scotland                        |
| Northern Ireland                      |                                       |

4. What services do you offer? (tick all that apply)

| Service                                      | Options                                      |
|----------------------------------------------|----------------------------------------------|
| Specialist palliative care inpatient         | Specialist palliative care community / homecare |
| Hospital Inpatient                           | Hospital outpatient                          |
| Specialist palliative care day hospice       |                                              |

5. Do you offer a service to non-cancer patients?

| Yes                                      | No                                      | Don’t Know |
|-----------------------------------------|-----------------------------------------|------------|

6. Do you offer Specialist Palliative Care services to heart failure patients?

| Yes                                      | No                                      | Don’t Know |
|-----------------------------------------|-----------------------------------------|------------|

7. Do you believe Specialist Palliative Care services have a role in severe/end stage heart failure patients?

| Yes                                      | No                                      | Not sure |
|-----------------------------------------|-----------------------------------------|-----------|
7 a. If yes, in your view, when is the most appropriate time for referral? (tick all that apply)

| o initial diagnosis | o deterioration in symptoms | o consideration of advanced heart failure management (eg. implantable devices, transplants etc) |
|---------------------|----------------------------|------------------------------------------------------------------------------------------------|
| o recurrent hospital admissions | o end-stage/end-of-life |                                                                                             |

7 b. If no, why not? (tick all that apply)

| o lack of resources | o lack of beds (including respite bed facilities) | o implications for staff training |
|---------------------|--------------------------------------------------|----------------------------------|
| o organisational decision | o lack of expertise | o none/few referred (by cardiology or GP) |
| o cardiac professionals can do this | o Unable to give IV therapy (please state reason in free text box) | o any other reasons (free text) |

8. How many referrals have you received in the last year where heart failure was the main diagnosis?

| o 0-10 | o 11-25 | o 26-50 | o >51 |

9. How many patients in total are currently under your Specialist Palliative Care services?

| o Hospice inpatient | o Community | o Day Care | o Hospital outpatient | o Hospital inpatient |
|---------------------|-------------|------------|-----------------------|----------------------|
| ..................... | ............... | .............. | ................ | ...................... |

10. How many patients, with heart failure as the main diagnosis, are currently under the care of your Specialist Palliative Care services, if any?

| o Hospice inpatient | o Community | o Day Care | o Hospital outpatient | o Hospital inpatient |
|---------------------|-------------|------------|-----------------------|----------------------|
| ..................... | ............... | .............. | ................ | ...................... |

11. Does your service have specific referral criteria for heart failure patients?

| o Yes | o No | o Don't Know |
|-------|------|--------------|
11 a. If yes, what are they?

| Yes | No | Don't Know |
|------|----|------------|
| recurrent hospital admissions with decompensated heart failure | inappropriateness of further hospital admission | severity of heart failure |
| | | other (please specify) |

12. Do you have specific treatment guidelines for managing heart failure?

| Yes | No | Don't Know |
|-----|----|------------|

12 a. If so, what are they? (tick all that apply)

| Yes | No | Don't Know |
|-----|----|------------|
| end-of-life pathways | breathlessness management pathways | symptom control guidelines |
| | | other (please specify) |

13. Do you have local collaborative care between yourselves and your local heart failure services (including community and hospital based care)?

| Yes | No | Don't Know |
|-----|----|------------|

13 a. If so, what?

| Yes | No | Don't Know |
|-----|----|------------|
| mutual education | joint working | steering/working groups |
| | | MDT meetings |
| | | other (please specify) |

14. Have you ever experienced problems with deactivating an ICD in a terminal patient?

| Yes | No | If yes, please elaborate |
|-----|----|--------------------------|

15. In your experience, how often have ICD deactivation and discussions surrounding end-of-life care eg. "Do Not Resuscitate" decision making, been discussed/addressed, prior to referral to SPC services?

| Mostly | Sometimes | Rarely | Never |
|--------|-----------|--------|-------|

16. Any other comments?

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Thank you for your time.