

PEER REVIEW HISTORY

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ARTICLE DETAILS

TITLE (PROVISIONAL)	Unplanned admissions and the organisational management of heart failure: a multi-centre ethnographic, qualitative study
AUTHORS	Simmonds, Rosemary; Glogowska, Margaret; McLachlan, Sarah; Cramer, Helen; Sanders, Tom; Johnson, Rachel; Kadam, Umesh; Lasserson, Daniel; Purdy, Sarah

VERSION 1 - REVIEW

REVIEWER	Wingham, Jennifer Royal Cornwall Hospitals Trust, Research and Development
REVIEW RETURNED	13-Apr-2015

GENERAL COMMENTS	<p>This study addresses an important area of research especially as heart failure is one of the leading causes for hospital admissions. It does much to provide a rich narrative for the actual experiences of patients, caregivers and the health service.</p> <p>I have some comments to enhance the quality of the paper.</p> <p>Title</p> <p>The term 'management of heart failure' covers many aspects of care. I suggest clarifying that you mean organisational management. Readers of a medical journal may well be expecting issues of medication management, investigations etc.</p> <p>Abstract</p> <p>In the objectives the second sentence would benefit from adding 'identify the' between 'and' and 'barriers'.</p> <p>In participants the follow up time period seems to be different from that presented in the main paper. Please clarify.</p> <p>In the conclusion add 'increased the' between 'and' and 'likelihood'.</p> <p>Introduction</p> <p>The last sentence in paragraph 3 (In studies) needs rewording – you use the term relational continuity twice, I wondered if the second related to continuity of management, if not it doesn't need to be repeated.</p> <p>I suggest that as the study includes caregivers that the introduction should include a couple of lines about them. This could be for</p>
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	<p>example, the impact of being a caregiver and factors affecting their decision making about when to call for help.</p> <p>You say that there are no existing studies exploring why admissions continue to be common. Please add 'to our knowledge' before there are no existing. It might be worth reading Evangelista's work on the topic about medicines use.</p> <p>In paragraph 4 the justification for ethnographic methods should be moved to the start of the methods section.</p> <p>Methods</p> <p>This section lacks detail about the processes you used. Please add in who approached the potential participants, and how (post, during clinics, home visits etc). How many were approached? Who obtained consent and were the researchers known to the participants. Were the health professionals in the study caring for the participants? Where did the interviews take place? In the results you use the term impromutu interviews – there is nothing in the methods about these interviews.</p> <p>Much more detail is required about diaries- how long were they completed for? What questions did they cover? How were the data sources triangulated in the analysis?</p> <p>What were you looking for in the medical records and how did you collect the data? Do you mean GP records or hospital notes?</p> <p>More detail is required about the sites of collection. The county may help, were they rural or urban settings, what was the size of the GP practice? What heart failure services were available in the areas of study?</p> <p>Where did you store the audio recordings?</p> <p>Analysis – It was lovely to see the involvement of your advisory group. Did they receive training in qualitative techniques?</p> <p>Results</p> <p>Please provide a table with some basic details about the participants, for example NYHA, age range as well as the average, length of time with HF, other co-morbid conditions, relationship to caregivers.</p> <p>When was the study conducted?</p> <p>I'm not clear how many interviews each participant gave, especially with the impromptu interviews and the follow up period. From the numbers given it seems that not all patients and caregivers were interviewed. If this is correct please justify how and why you chose which ones to interview or if the declined to be interviewed.</p> <p>You refer to centre A and make a really important point about organisation fragmentation. It would really help to have a box with a</p>
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	<p>description of the centres – see comments about the centres in the methods.</p> <p>Your figure1 needs substantial tidying – the arrows should go to the edge of the boxes. What do the red boxes mean? It might be more helpful to see a flow diagram instead.</p> <p>Page 14 – patient information and education – to understand this we need to know what was provided in the centres- was there a lack of services? You can move the sentence ‘Both education and self-management...’ to the discussion.</p> <p>Discussion</p> <p>You say that ‘in most but not all of the study areas (please be consistent with terms) fragmented services and poor managerial continuity created barriers...’ This suggests that there are other reasons for hospital admission. These need to be reflected in the results and comments added in the discussion. A summary of the findings would be helpful – use your figures 1 and 2 and explain why you chose a pyramid model.</p> <p>The discussion lacks depth about overcoming the barriers to reduce hospital admissions. More can be said for clinicians – there is qualitative research about end of life discussions. What about monitoring the condition? – you don’t mention telemonitoring and many areas are using this to assist management of heart failure.</p> <p>There are other limitations around selection procedures. Concordance is the wrong term here. You need to comment on the issue of co-morbidities – were all the admissions due to heart failure.</p> <p>The discussion focusses on patients and health care professionals but lacks discussion about the caregivers.</p> <p>Overall an interesting study that needs more explanation in the paper.</p>
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REVIEWER	Clark, Alex University of Alberta, Faculty of Nursing
REVIEW RETURNED	04-May-2015

GENERAL COMMENTS	<p>An important topic explored in a vulnerable clinical population.</p> <p>Introduction and background</p> <p>The paper focuses a lot on the UK - and a greater international feel would benefit given the wide readership of this journal.</p> <p>There is a lot of past qualitative research on heart failure (100 plus qualitative studies) - more of this should be acknowledged in the</p>
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	<p>background, including published reviews of treatment help seeking during heart failure (http://www.ncbi.nlm.nih.gov/pubmed/22721677).</p> <p>The study is generally well designed. Were any criteria used to measure 'severe or difficult to manage heart failure? This seems quite vague and subjective.</p> <p>How were the interview transcripts developed? What informed the topic selection? What type of interviews were subsequently done? Was ethical approval granted? This should be stated overtly.</p> <p>Re analysis, how were the accounts of patients and professionals handled together? How were they triangulated and what happened when they conflicted.</p> <p>Given the large volume of past published research, the findings could be better integrated into this. Limitations are recognized.</p>
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VERSION 1 – AUTHOR RESPONSE

Reviewer 1

Reviewer(s)' Comments to Author:

This study has much to say at a time when services are under constant review and as commissioners struggle to find clinical and cost effective pathways for complex patients. I have provided a review that includes what is missing.

Some of the information you need to add to the paper you wrote in your COREQ statement. I hope to see this study published in the future.

Title

The term 'management of heart failure' covers many aspects of care. I suggest clarifying that you mean organisational management. Readers of a medical journal may well be expecting issues of medication management, investigations etc.

The title has been updated (page 1)

Abstract

In the objectives the second sentence would benefit from adding 'identify the' between 'and' and 'barriers'.

Added page 2

In participants the follow up time period seems to be different from that presented in the main paper. Please clarify.

This has been corrected (page 6)

In the conclusion add 'increased the' between 'and' and 'likelihood'.

Added page 2

Introduction

The last sentence in paragraph 3 (In studies) needs rewording – you use the term relational continuity twice, I wondered if the second related to continuity of management, if not it doesn't need to be repeated.

Duplicate phrase deleted (page 4)

I suggest that as the study includes caregivers that the introduction should include a couple of lines about them. This could be for example, the impact of being a caregiver and factors affecting their decision making about when to call for help.

The following has been added to the paper:

Introduction(page 5):

The impact of caring for a patient with heart failure places considerable burden on informal carers, particularly in those patients with advanced heart failure who are coming to the end of life.

Plus paragraphs to the results (page 13) and discussion sections (page 23) – see below.

You say that there are no existing studies exploring why admissions continue to be common. Please add 'to our knowledge' before there are no existing. It might be worth reading Evangelista's work on the topic about medicines use.

Phrase 'to our knowledge added (page 5)

In paragraph 4 the justification for ethnographic methods should be moved to the start of the methods section.

We felt this justification was best left as part of the introduction but would be happy to take the editor's advice on this.

Methods

This section lacks detail about the processes you used. Please add in who approached the potential participants, and how (post, during clinics, home visits etc). How many were approached?

The following text has been added to page 5: 'Potentially eligible participants were identified at one site by screening of patients on the hospital ward or in heart failure clinics and at the other two sites by health care professionals in heart failure clinics and general practices. Patients at the first site were then approached directly in person by a health services researcher external to the study who invited patients to consider participation in the study. At the other two sites potential participants identified from heart failure clinics and general practices were sent letters of invitation. If potential participants at all three sites indicated they were interested in the study they were then contacted by the study team. Overall, of the patients who gave their consent to being contacted by the study team, 13 declined to participate. Three patient participants died during the course of the study.

Who obtained consent and were the researchers known to the participants.

Informed consent was obtained by the researchers who were not known to participants. These details have been added to page 6.

Were the health professionals in the study caring for the participants?

The following text has been added to page 6: 'The majority of health care professionals in the study were caring for study participants and were observed delivering care. A minority of health professional participants were caring for people with heart failure who were not participating in the study. These health care professionals took part in pre-arranged interviews about their general experiences of

caring for people with heart failure and what might trigger an unplanned hospital admission.'

Where did the interviews take place? The interviews took place in health care settings and patients homes (added to page 7)

In the results you use the term impromptu interviews – there is nothing in the methods about these interviews.

The impromptu interviews were described in the original methods section (page 6)

Much more detail is required about diaries- how long were they completed for? What questions did they cover? How were the data sources triangulated in the analysis?

Details have been added to pages 7 (information on diaries) and 8 (analysis)

Page 7:

Four patients and 6 carers agreed to write diaries. Diaries were completed for a period of between three weeks and ten months. Participants could choose to opt out of this task at any point. There were two topic guides posing questions for the diarist to address, one for carers and one for patients. For patients we asked for example: what was the health or social care received that day; what was the purpose of the treatment/care; what worries them the most.

Page 8:

The first stage of data triangulation was at an individual patient level. We used chronological charts to track and compare events and issues in patient and carer stories arising from field notes, interviews and diaries, with patients' medical record event 'stories'. We then combined the key elements of personal and medical stories into situational maps for each patient (following methods outlined in Situational Analysis; Clarke 2005) and examined the maps in relation to 5 questions: who and what are in the situation; who and what matters in the situation; what elements make a difference in the situation; what are the physical triggers for admission; what can tip the balance for admission. After synthesising key themes from the situational maps, within each research centre, the second stage of data triangulation involved comparison across the three research centres with input from our patient/carers advisory group and professional advisory group.

What were you looking for in the medical records and how did you collect the data? Do you mean GP records or hospital notes? Page 7 amended to read: included information from patient primary care and secondary care medical records comprising consultations, investigations, medication and correspondence relating to all admissions and outpatient appointments,

Following detail added to page 9: Events in patients' medical records were summarised and entered into a chronological chart which was divided into two columns, one for the patient/carers story and one for the medical story. We were examining and contrasting individual patient/carers experiences with the medical story and identifying potential risk factors for unplanned admissions.

More detail is required about the sites of collection. The county may help, were they rural or urban settings, what was the size of the GP practice? What heart failure services were available in the areas of study?

We have not identified the study areas in line with recommended best practice in publishing research findings which could potentially identify study participant. However, we have added the following information to page 5: The three study sites were a mix of urban and rural settings covering large geographical areas and with variable access to heart failure specialist nurse led clinics.

Where did you store the audio recordings? Data were stored on a secure server (added to page 8)

Analysis – It was lovely to see the involvement of your advisory group. Did they receive training in qualitative techniques? The patient and carer advisory group received informal training in qualitative techniques

Results

Please provide a table with some basic details about the participants, for example NYHA, age range as well as the average, length of time with HF, other co-morbid conditions, relationship to caregivers.

We have not provided details of this nature about the participants in line with recommended best practice in publishing research findings which could potentially identify study participants

When was the study conducted? 2011-2013 (added to page 6)

I'm not clear how many interviews each participant gave, especially with the impromptu interviews and the follow up period. From the numbers given it seems that not all patients and caregivers were interviewed. If this is correct please justify how and why you chose which ones to interview or if the declined to be interviewed.

The following detail from the study protocol has been added to page 6:

In-depth interviews were planned with a sub-sample of patients or carers/family members (around eight at each site). To include around four patients or their carers experiencing exacerbations/hospital admissions and four without hospital admissions during the previous six months (thereby including different patient trajectories and severities). Recorded fieldwork conversations (impromptu interviews) with patients, carers and health professionals were conducted and analysed as an integral part of the ethnographic fieldwork.

Further information has been added to page 10: All patients (and carers where they participated) were interviewed about the patient's 'heart failure journey' at the beginning of participation in the study. Some of these interviews were in depth interviews and others were shorter 'impromptu' interviews. All patients were also invited to take part in an exit interview. No patients declined to participate in an exit interview but not all were available or able to do this. Additional impromptu interviews were then conducted at different points in the study.

You refer to centre A and make a really important point about organisation fragmentation. It would really help to have a box with a description of the centres – see comments about the centres in the methods.

Please see comments above

Your figure1 needs substantial tidying – the arrows should go to the edge of the boxes. What do the red boxes mean? It might be more helpful to see a flow diagram instead.

Please see revised figure 1 attached

Page 14 – patient information and education – to understand this we need to know what was provided in the centres- was there a lack of services?

We have addressed service provision in the discussion section

You can move the sentence 'Both education and self-management...' to the discussion.

This sentence has been moved to the discussion (page 24)

Discussion

You say that 'in most but not all of the study areas (please be consistent with terms) fragmented services and poor managerial continuity created barriers...' This suggests that there are other reasons for hospital admission. These need to be reflected in the results and comments added in the discussion

The start of this sentence has been amended to be consistent with the results and read: 'In all three of the study areas..' (page 19) The other reasons identified for admission are described in the results and discussion section.

A summary of the findings would be helpful – use your figures 1 and 2 and explain why you chose a pyramid model. We have included a summary of the study findings in paragraphs 1 and 2 of the discussion, in line with BMJ Open guidance. We have used figure 2 in the results and discussion sections to explain that we identified a number of points in patient pathways where risk of hospital admission is increased. We have also revised it so it is no longer a pyramid.

The discussion lacks depth about overcoming the barriers to reduce hospital admissions. More can be said for clinicians – there is qualitative research about end of life discussions. What about monitoring the condition? – you don't mention telemonitoring and many areas are using this to assist management of heart failure.

The following paragraphs have been added to the discussion:

'The reduction of hospital admissions, for conditions such as heart failure, requires system integration between primary and secondary care. The current barriers encompass lack of patient knowledge, diminishing primary care co-ordination, and specialist care that needs to be available outside of acute hospital care in the community. Whilst innovations such as tele-monitoring are being developed to support these integration gaps, on their own they are unlikely to overcome system barriers which were illustrated by patients in our study.'

The data supporting the efficacy of telemonitoring on reducing hospital admissions is mixed. Recently reported clinical trials of telemonitoring (JAMA Intern Med. 2015 May 1;175(5):725-32, J Med Internet Res. 2014 Dec 11;16(12):e282., J Card Fail. 2014 Jul;20(7):513-21) have not demonstrated the positive impact on hospital admissions found from a systematic review based on smaller studies (Eur J Heart Fail. 2011 Sep;13(9):1028-40).'

As we outline above, the data supporting the efficacy of telemonitoring on reducing hospital admissions (the outcome raised by this reviewer) is mixed. A Cochrane review (summarised in Eur J Heart Fail. 2011 Sep;13(9):1028-40.) demonstrated that in eight small trials, telemonitoring had a small effect on all cause hospital admissions. However, since that review was published much larger trials have reported (JAMA Intern Med. 2015 May 1;175(5):725-32, J Med Internet Res. 2014 Dec 11;16(12):e282., J Card Fail. 2014 Jul;20(7):513-21) which have not demonstrated these benefits, which suggests that an updated systematic review is needed. We have also added a point to the 'Strengths and Limitations' section as a limitation.

We agree that some health systems have been introducing remote monitoring and support mechanisms for patients with heart failure. Although retrospective analyses of such projects is encouraging in terms of outcomes (J Med Internet Res. 2015 Apr 22;17(4):e101, Popul Health Manag. 2014 Dec;17(6):340-4.) this may be because patients choosing a remote monitoring system

have a better prognosis than those patients who do not choose such care models outside of a randomised controlled trial (J Telemed Telecare. 2015 Mar 11. pii: 1357633X15574947. Epub ahead of print).

There are other limitations around selection procedures. Concordance is the wrong term here. Concordance has been replaced by agreement (page 23)

You need to comment on the issue of co-morbidities – were all the admissions due to heart failure. All admissions were recorded but only those directly related to heart failure were included in this analysis (added to page 10)

Where co-morbid conditions and their treatments were relevant to the patient and carer experience of illness and barriers to access to care, they were mentioned by all interviewees (e.g. Box 1, para (a), Box 3 all paras demonstrate the impact of presumed comorbid conditions and how they can delay a diagnosis of acute exacerbation)

The following paragraph has been added to the discussion section:

Whilst in our study, patient participation was directly related to heart failure admissions; the analysis also showed that comorbidity was an important factor in these hospital admissions, and which is supported by current evidence. Comorbidity creates the clinical barrier which hinders acute heart failure management and further developments need to consider how this critical issue is addressed. [Reference: Braunstein J, Anderson G, Gerstenblith G, et al. Noncardiac comorbidity increases preventable hospitalizations and mortality among medicare beneficiaries with chronic heart failure. J Am Coll Cardiol. 2003;42(7):1226-1233. doi:10.1016/S0735-1097(03)00947-1.]

The discussion focusses on patients and health care professionals but lacks discussion about the caregivers. Overall an interesting study that needs more explanation in the paper.

We have added a paragraph to the results section (page 13)

'The lack of continuity and barriers to obtaining care placed a particular burden on carers. Carers' diaries and ethnographic observations highlighted the emotional impact on the carer of the patient's condition and their critical role in encouraging the patients to access health services and acting as the patient's 'champion' (Box 1).'

and to the discussion (page 23) ' Besides giving physical, emotional and practical support, most carers took on an 'ambassadorial' role in relation to the people they cared for. Carers chased up lost medical notes/letters and played a key role in unravelling problems caused by poor communication and co-ordination across fragmented health care systems. As carers gained experience they became more proactive in challenging the organisation and provision of care on behalf of the person they cared for. In this respect carers shouldered a lot of stress and responsibility, even though most of them had their own health problems to deal with.'

Reviewer 2

Reviewer Name Alex Clark

Institution and Country University of Alberta, Canada

Please state any competing interests or state 'None declared': None declared

Please leave your comments for the authors below

An important topic explored in a vulnerable clinical population.

Introduction and background

The paper focuses a lot on the UK - and a greater international feel would benefit given the wide readership of this journal.

We have added references from the international literature to the introduction and discussion

There is a lot of past qualitative research on heart failure (100 plus qualitative studies) - more of this should be acknowledged in the background, including published reviews of treatment help seeking during heart failure (<http://www.ncbi.nlm.nih.gov/pubmed/22721677>).

To address the reviewer's suggestion that previous qualitative research should be acknowledged, we have added the following to page 4:

"Previous qualitative studies have provided some insight into factors which may underlie unplanned hospital admissions in patients with heart failure. For example, a qualitative meta-synthesis of literature on help-seeking in heart failure patients identified a number of barriers to timely access to treatment, including uncertainty over the need for help-seeking with fluctuating symptoms, uncertainty about who to contact, fear of hospitals, and patients' attribution of symptoms to other causes (Clark et al., 2012). However, studies have mainly focused on patient factors, such as self-care (e.g., Schnell et al., 2006), knowledge (Agard et al., 2004) adherence to treatment (Scotto, 2005), health care professional factors, for instance beliefs and attitudes (Fuat et al., 2003; Fuat et al., 2005) experience in managing heart failure patients (Philips et al., 2004) in isolation, with a dearth of qualitative literature exploring how these different factors may interact. To develop an understanding of the interactions between patient, carer, health care professional and system factors in unplanned hospital admissions, an ethnographic approach was adopted."

The study is generally well designed. Were any criteria used to measure 'severe or difficult to manage heart failure? This seems quite vague and subjective.

The key criterion was an unplanned admission for heart failure in the previous six months, clinicians were then asked to consider of the patient had in their view severe or difficult to manage heart failure. We did not include NYHA criteria as some patients in primary care do not have a NYHA classification.

We have revised the information on page 5 to clarify this:

'The inclusion criteria were adult patients with an unplanned hospital admission for heart failure during the preceding 6 months and who the referring clinician considered had severe or difficult to manage heart failure (with or without physical or mental health co-morbidities).'

How were the interview transcripts developed? What informed the topic selection? What type of interviews were subsequently done?

Following added to page 7: 'Topic guides were developed based on a review of the relevant literature, expert advice from the Study Advisory Group and key informant interviews with staff involved with the management of patients with heart failure'. More detailed information on interviews added to page 6-9.

Was ethical approval granted? This should be stated overtly.

The study was approved by NRES Committee South West – Frenchay (reference 12/SW/0104).

These details of ethical approval were included in the original manuscript (page 26)

Re analysis, how were the accounts of patients and professionals handled together? How were they triangulated and what happened when they conflicted.

The following information has been added to page 8: Data from professionals and patients were compared systematically across all transcripts and common narratives were used to inform the thematic analysis. The data were used together as part of an integrated thematic analysis where interview quotations and observational data were grouped under the relevant themes and compared

for similarities and differences. This way we were able to identify common themes from patients and healthcare professionals, highlighting similarities and differences in relation to the care of patients with heart failure. Conflict of opinion/views was treated as a naturally occurring finding highlighting the diversity of perspectives and the complexity of chronic illness management. The study did not seek to capture 'factual' information as such, and aimed to examine the richness of views and the complexity of clinical and patient related decision making.

Given the large volume of past published research, the findings could be better integrated into this. Limitations are recognized.

Additional paragraphs have been added to the discussion highlighting previous research and the implications of this study in this context.

VERSION 2 – REVIEW

REVIEWER	Wingham, Jennifer Royal Cornwall Hospitals Trust, Research and Development
REVIEW RETURNED	08-Jun-2015

GENERAL COMMENTS	The reviewer completed the checklist but made no further comments.
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REVIEWER	Clark, Alex University of Alberta, Faculty of Nursing
REVIEW RETURNED	24-Jun-2015

GENERAL COMMENTS	<p>Heart failure disease management is important and needs to be better. This paper adds useful knowledge using appropriate ethnographic methods to inform and improve heart failure healthcare. The use of observational methods is a particular strength because almost all of the 100+ qualitative studies of heart failure patients use focus group or interview methods. This means they are by nature filtered by participants.</p> <p>The paper is generally well written, the methodology is well founded and justified. Findings are well detailed and substantiated by the data - relevant quotes being included.</p> <p>It could be improved by:</p> <p>Methods</p> <ol style="list-style-type: none"> 1. More details of the recruitment sites / setting (e.g. were these mixed urban / rural, teaching hospital?), 2. How was the sample size determined? Make reference to ethnographic field work principles here. 3. What did the initial field work involve? How was the sub-sample of patients selected for follow up interviews? How were the topics for the interviews developed? The advantages of observational methods could be addressed in the text more overtly. 4. How was quality or rigour in the study maintained? More on this
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	<p>could be explained. What happened in instances in which the accounts of the health professionals and patients were mutually exclusive?</p> <p>5. A table providing summary recommendations for future trials and clinical interventions would be a useful addition.</p> <p>6. I recommend the title of the paper indicate it is 'qualitative' research.</p>
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VERSION 2 – AUTHOR RESPONSE

1. More details of the recruitment sites / setting (e.g. were these mixed urban / rural, teaching hospital?)

On Page 5 – Methods – participants and recruitment – first paragraph - we have added more information about the GP recruitment sites.

On Page 6 – Methods – participants and recruitment – first paragraph - we have also added information about the two hospital trust recruitment sites.

On Page 6 we had already provided a description of the three sites in terms of urban / rural in the previous manuscript.

2. How was the sample size determined? Make reference to ethnographic field work principles here.

On Page 5 - Methods – participants and recruitment – first paragraph - we have now provided a rationale for the sample size that is based on ethnographic field work principles.

3. (a) What did the initial field work involve?

On Page 6: Data Collection - first paragraph – we have added some clarification.

(b) How was the sub-sample of patients selected for follow up interviews?

On Page 6: We have highlighted the clarification for how the sub-sample of patients were selected for follow up interviews.

(c) How were the topics for the interviews developed?

On Page 7: We have highlighted the information about the development of the topic guide.

(d) The advantages of observational methods could be addressed in the text more overtly

On Page 5: Introduction, last paragraph. We have added a little more to the text about the advantages of using observational methods.

4. (a) How was quality or rigour in the study maintained?

On Page 8: Analysis - third paragraph – we have added a paragraph on how we achieved and maintained qualitative rigour.

(b) What happened in instances in which accounts of the health professionals and patients were

mutually exclusive?

On Page 9: Analysis – fifth paragraph – we have added some further clarification on how we analysed and compared patient / carer accounts with medical accounts. Identifying any dissonance between these.

5. A table providing summary recommendations for future trials and clinical interventions would be a useful addition.

Our research conclusions highlighted (a) systems issues, such as fragmented care and lack of continuity between health providers and (b) the need for improved and ongoing communication between clinicians and patients / carers around HF diagnosis, education and end of life care. We have summarised the implications of these findings for clinicians, policy makers and researchers on page 25. We did not feel that a summary table of recommendations for future trials or clinical interventions added to this or fitted with the BMJ Open format but would be happy to add this if the Editors advise.

6. I recommend the title of the paper indicate it is 'qualitative' research

We have added the word 'qualitative' to the title.