Author’s response to reviews

Title: Palliative care specialists’ perceptions concerning referral of haematology patients to their services: findings from a qualitative study

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Author’s response to reviews:

Dear Editor,

Re: Palliative care specialists’ perceptions concerning referral of haematology patients to their services: findings from a qualitative study (PCAR-D-17-00183)

We wish to thank both reviewers for their insightful and helpful comments. We have amended our paper accordingly and consider that it is now stronger and clearer.

New references added into the text have been included in the list of references.
We have addressed technical comments first, followed by comments made by reviewer 1, then reviewer 2.

TECHNICAL COMMENTS

Comment: FD: Missing “Results” section, “Consent of Publication”

Response: We have inserted the following text into the manuscript (page 22)

Consent for publication

Consent for publication was gained at the time of consent to participate for all interviewees.

RESPONSE TO REVIEWER 1’S COMMENTS

Comment 1 relates to the Background section

Comment 1: The relevance and aim of the study are not clearly stated.

Response: We agree with the reviewer and have added new material into this section, as highlighted on pages 4-5 and shown below:

Specialist palliative care (SPC) is reported to have a positive effect on quality of life in some cancers [10,11], and early access to these services is recommended alongside disease directed treatment [12,13]. For haematological malignancies, evidence suggests that palliative care specialists can optimise symptom management and communication; facilitate more effective
coping, accepting and planning for patients (and family members) in dealing with prognostic uncertainty; and act as a communication bridge between the haematologist and the patients, particularly in situations where patients do not fully discuss their fears and concerns with the haematology team [14]. Despite this, research from the UK, United States (US) and elsewhere, indicates that patients with these diseases are not referred to SPC and hospice services as often as people with other cancers [15–18]; and those who access hospice care have poorer health at the time of admission and shorter lengths of stay [19,20]. These factors are often considered to reflect poor quality end of life care [21].

Referral practices are increasingly the focus of international research (based mainly on reviews of patient records, but also some qualitative studies with haematologists), which provide insights into reasons for late or non-referral of patients with haematological malignancies [22–26]. A recent integrative systematic review, for example, highlights reluctance on the part of haematologists to refer to SPC services due to differing treatment goals, prognostic difficulties, and preference of haematology specialists to manage palliative care, as barriers to referral [27]. However, knowledge of the perspectives of SPC clinicians concerning barriers and facilitators to referral is largely absent [20]. Our study, the first of its kind in the UK, was designed to specifically address this deficit, through interviews with SPC doctors and nurses. The aim of the study was to capture data that enhance understanding of factors that promote or prevent the integration of palliative care and haematology services.

Comments 2 and 3 relate to the Methods section

Comment 2: We should refer to limitations to generalisability of the study findings in the Discussion.
Response: We have inserted new text into the Discussion section (pages 19-20), relating to the limitations of the study.

Qualitative methods are suited to exploration of phenomena about which little is known (28) and the aim of purposeful sampling is to select ‘key informants’ who can provide rich description of the phenomena being studied. Our study sample yielded data that provide new insights into an important but under-researched area and sensitize readers to new ways of thinking. Representativeness is not usually a key aspiration in qualitative research, which has implications for the generalizability of findings. Instead of using the term ‘generalizability’, it is more useful to talk about the ‘transferability’ of findings in relation to their relevance for understanding similar issues and processes (31). Extrapolation of findings should therefore take into account any study-specific contextual factors (e.g. health-care infrastructure; universal health-care coverage etc.) that may limit transferability (51).

Comment 3: It would be useful to clarify why the experienced qualitative researcher checked the coding of only two interviews.

Response: We agree with the reviewer and apologise for our lack of clarity. We have expanded the Methods: Data Analysis section (pages 5-6) which now fully explains the role of the independent researcher. To clarify, this was not to ‘prove’ the reliability of coding (which is why the researcher was not asked to check coding of all interviews) but rather to help the researchers think critically about the coding decisions that were made and the development of themes. Involvement of an independent researcher in this way can help to highlight where analysts’ assumptions and expectations may have blinkered them to alternative interpretations of the data, or where they may have overlooked material that could enrich their interpretation. Used in this way, independent comments on coding and theme development can facilitate reflexivity on the part of the analyst(s) (see King N, Horrocks C. Interviews in qualitative research. London: Sage;
The newly expanded section on Data analysis is reproduced below:

Data analysis

Transcripts were analysed for thematic content using the ‘Framework’ method (30), whereby a coding scheme and analytical framework were developed, drawing on the topic guide, but incorporating new lines of enquiry identified in the data. Coding and classification was systematic and inductive, involving data familiarisation through reading/re-reading transcripts, coding transcripts and developing analytical categories; followed by identification of common patterns or ‘themes’, interpreted through seeking meaning, salience and connections. Negative or ‘deviant’ cases were actively sought in the data (31), in order to develop and refine the analysis. Data handling and charting, and comparison within and between cases, was facilitated through use of electronic spreadsheets. An overview of the data analysis process is provided in Figure 1, with examples to illustrate how themes were developed.

Two researchers were involved in the data analysis (DM and DH, both qualified nurses with extensive experience of using qualitative methods in applied health services research settings, and particularly haematology). DM read all of the transcripts and carried out initial identification and compilation of codes, while employing reflective notes and memos. These formed the basis of regular discussions (DM and DH), initially to agree and refine codes, and later to discuss emerging themes. Disagreements during discussions offered insights that were useful for refining data coding and interpretation (32). An experienced qualified researcher (independent of the study) was asked to assess the ‘fit’ of the coding scheme in relation two interviews (33) and confirmed that the strategy was comprehensive and appropriate (34).
Comment 4 relates to the Findings section

Comment 4: The themes identified are difficult to categorise or group, making it challenging for the reader to follow. Reviewer 1 suggests that it would be useful to include a paragraph at the beginning of the findings section explaining the way the themes were structured/grouped to facilitate reading of the manuscript. Reviewer 1 also comments that some topics seem to overlap.

Response: We thank the reviewer for these very helpful comments, which have led us to restructure presentation of the findings. We now provide a brief paragraph at the beginning of the Findings section (page 6) explaining the way the themes have been grouped/structured to facilitate reading of the Manuscript. Themes have been re-organised into barriers and facilitators, as an aid to the reader. Also, some topics have been combined, in response to Reviewer 1’s comment that some topics seemed to overlap. Comment boxes have been inserted into the manuscript to clarify this restructuring process (see pages 6-16).

Consequently, the results section of the abstract (page 2) has also been restructured using the context of barriers and facilitators. It now reads as follows:

Study participants identified a range of barriers and facilitators influencing the referral of patients with haematological malignancies to SPC services. Barriers included: the characteristics and pathways of haematological malignancies; the close patient/haematology team relationship; lack of role clarity; late end of life discussions and SPC referrals; policy issues; and organisational issues. The main facilitators identified were: establishment of inter-disciplinary working patterns (co-working) and enhanced understanding of roles; timely discussions with patients and SPC referral; access to information platforms able to support information sharing; and use of indicators to ‘flag’ patients’ needs for SPC. Collaboration between haematology and SPC was perceived as beneficial and desirable, and was said to be increasing over time.
Comment 5 relates to the Discussion section

Comment 5: It is not clear what this article adds to the current literature. Reviewer 1 highlights the need to clarify in the introduction why SPC perspectives are important and to re-write the discussion focussing on the new aspects that the perspectives of SPC clinicians add to the current literature.

Response: We have inserted a new paragraph at the beginning of the Discussion section (page 16) which highlights the new perspectives of SPC clinicians revealed by the study; there are references as to how these relate to the broader literature in the discussion that follows.

This is the first UK study to explore SPC doctors’ and nurses’ perceptions about the referral of patients with haematological cancers to their services. Our findings overlap those arising from research conducted with haematologists (22–24), thus confirming and complementing these studies’ results. New insights we offer include SPC clinicians’ perspectives that their role is not always well understood by haematologists, as well as their perceptions of the importance of co-location of services in promoting and enhancing role clarity and closer working patterns. Improvements such as shared access to information platforms across the specialist disciplines and different care settings were described by study SPC clinicians as fundamentally necessary to enhance patient referral and integrated care delivery. The need for indicators or ‘triggers’ to promote early referral of haematological patients identified in our study has previously been reported in research from the US (26); our UK findings re-inforce these earlier reports, signalling widespread recognition of the requirement for further developments in this area.

RESPONSE TO REVIEWER 2’S COMMENTS

Comment 1 relates to the Background section
Comment 1: Notes the clear aim of the research, and the importance of the contribution of the study to the literature.

Response: We thank Reviewer 2 for their favourable comments.

Comment 2 relates to the Methods section

Comment 2: The methods used and the topic guide were appropriate.

Response: None required.

Comment 3 relates to the Data Analysis

Comment 3: Further information on data analysis and use of the ‘Framework’ approach is requested. A series of questions are posed relating to specific aspects of data analysis, which we address below:

Response: We have expanded this section relating to data analysis (page 6) to incorporate our response to points raised by the reviewer (see below). We have also included a figure (Figure 1), which illustrates the steps followed by the researchers in using the Framework approach to data analysis, giving examples of how themes were developed.

The amended text now reads:
Data analysis

Transcripts were analysed for thematic content using the ‘Framework’ method (30), whereby a coding scheme and analytical framework were developed, drawing on the topic guide, but incorporating new lines of enquiry identified in the data. Coding and classification was systematic and inductive, involving data familiarisation through reading/re-reading transcripts, coding transcripts and developing analytical categories; followed by identification of common patterns or ‘themes’, interpreted through seeking meaning, salience and connections. Negative or ‘deviant’ cases were actively sought in the data (31), in order to develop and refine the analysis. Data handling and charting, and comparison within and between cases, was facilitated through use of electronic spreadsheets. An overview of the data analysis process is provided in Figure 1, with examples to illustrate how themes were developed.

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Comment 4 relates to the Results section

Comment 4: Use of quotes to support key themes is appropriate.

Response: None required.
Comments 5-7 relate to the Discussion section

We thank the reviewer for their positive comments on the significance of the issues raised in the Discussion section of the Manuscript and for highlighting their importance.

Comment 5: Omission of mention of co-location of services in the Discussion section of the Manuscript.

Response: We have amended the text of the Discussion (page 19) to include mention of the perceived effects of co-location on relationship building:

The importance of mutual understanding about roles was identified in another UK interview study exploring haematologists’ views about collaboration with palliative care services, along with consistent and flexible service provision (23). In our own study, co-location of services was considered an important means of promoting more integrated working patterns, through frequent opportunities for informal contact between clinicians that contributed to relationship building.

Comment 6: Best practice models have been described in the extant literature - suggests we include reference to work by McGrath P, Holewa H. Haematology and Palliative Care: Towards an Integrated Practice International Program of Psycho-Social Health Research (IPP-SHR)).

Response: We thank the reviewer for this helpful comment, and have included the reference and amended the text (page 18) accordingly:

Other ‘best practice’ models supporting integration of palliative care in haematology settings suggest early patient referral and a collaborative multi-disciplinary approach (44).
Comment 7: The manuscript highlights an extremely salient point - that the ‘upstream integration’ model of palliative care is at odds with UK policy/ commissioning guidance and may conflict with hospice admission criteria. Reviewer 2 suggests that authors may want to discuss if UK policy is also at odds with the WHO definition.

Response: We thank the reviewer for noting this important point. The text of the Manuscript has been amended (page 18) to incorporate reference to the WHO definition of palliative care.

Such ‘upstream’ integration, which negates the need to identify the end of life phase, has been suggested by others (14,39–42), including the World Health Organisation (43), who state that “palliative care is applicable early in the course of an illness, in conjunction with other therapies that are intended to prolong life”. This would enable patients receiving treatment with curative intent, who may deteriorate suddenly, to begin to forge a relationship with the SPC team prior to their input being required.

Comment 8: Our article is ‘important in its field’ and that it makes a ‘valuable contribution to the literature’.

Response: We thank the reviewer for these very positive comments on the Manuscript.

Reviewer 2: Suggested Revisions

Page 15, lines 10-17: Suggest re-phrasing the sentence: ‘Uncertainty (due to fluctuating trajectories, sudden deterioration and death, last ditch attempts at salvage, and indistinct transitions) was important…’
Response: We agree that this sentence was a little confusing and have re-phrased the sentence as suggested by the reviewer. It now reads:

Uncertainty (due to fluctuating trajectories, sudden deterioration and death, “last ditch” attempts at salvage, and indistinct transitions) was a significant barrier. Also important were the close connections between patients and the haematology team; late end of life discussions and SPC referrals; organisational issues (such as distant relationships with primary care and specialist palliative care practitioners and limitations to information platforms); lack of role clarity (perceived “either/or”, curative/palliative) approaches to treatment; and UK policy governing access to SPC services.