Author’s response to reviews

Title: Unmet needs of patients with cancer in their last year of life as described by caregivers in a developing world setting: A qualitative study

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Version: 1 Date: 31 Jul 2019

Author’s response to reviews:

Apt 1B Mira Flores
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28th July 2019.

The Editor
BMC Palliative Care.

Dear Sir/Madam,

Re: The last year of life: Unmet needs of recently deceased cancer patients as experienced by caregivers in a developed world setting. A qualitative study

Please see below my list of revisions in response to the editorial comments.

REVIEWER 1

1. Reporting is sometimes done in a quantitative way

Amendments were made in the following places with percentages or numbers removed and replaced by general terms:

RESULTS SECTION

MAJOR THEME: INSTITUTIONS

SUBTHEME MEDICAL AND NURSING CARE
SUBHEADING: SYMPTOM MANAGEMENT

Page 17, lines 7-8: Pain was the most commonly mentioned symptom, with all but two of the narratives describing uncontrolled pain.

Page 18, lines 1-2: Many caregivers reported more than three admissions in the last year of life;

SUBHEADING: COMMUNICATION

Page 18, line 23: Many of those interviewed described wanting more information

MINOR THEME: COMMUNITY

SUBTHEME: COMMUNITY PALLIATIVE CARE

Page 21, lines 1-2. Most caregivers reported that the patient’s wish had been to die at home but only about half achieved this.

DISCUSSION, SUB-HEADING: COMMUNICATION & ATTITUDES

Page 30, lines 10-11. Inadequate communication was cited by about half the participants as a major unmet need

2. Can the authors in the Introduction and Discussion frame and substantiate their results a bit more with literature about this topic from other resource-poor studies? E.g. page 31 Worldview

The following amendments were made:

BACKGROUND

Page 5, lines 11-24 and Page 6, 1-14. Findings of studies on palliative and end-of-life care in resource poor countries in India, the Middle East, Africa and the Caribbean, were cited.

DISCUSSION

Page 30, lines 16-17: Similar deficiencies in communication skills were described in a Jamaican study.
Findings were aligned with supernatural Illness beliefs in the Caribbean and among Afro-Caribbeans in general.

Opiophobia was discussed as an issue in resource poor as well as high income countries. Cancer fatalism as described in Jamaica and India were cited.

3. The results are mostly skewed towards the negative experiences. This is key in the conclusions as well. I wondered whether in your narratives, there were also positive experiences? E.g. patients whose pain was controlled, situations in which communication was adequate etc and if so, if we can learn from the differences between such cases.

Such a wealth of data emerged from this study that a decision was taken to use this paper to highlight only the more frequent and prominent negative themes to encourage redress. The title of the paper “Unmet needs of patients with cancer…” was selected to reflect this and hence positive themes were generally not reported here.

Some positive experiences were reported, but negative ones were by far the more common experience. A statement to this effect was inserted in the RESULTS SECTION, SUB-SECTION UNMET NEEDS, Page 10, lines 8-9.

There was one exception. Results revealed that staff of specific services were commonly noted to display excellent attitudes. This was noted in the RESULTS SECTION, SUBTHEME MEDICAL AND NURSING CARE, sub-heading Attitudes, Page 18, lines 6-8.

4. It was suggested that language be adjusted to reflect that the results are framed in the experiences of the caregivers. The following amendments were made:

RESULTS SECTION

MAJOR THEME INSTITUTIONS

SUB-THEME GENERAL SERVICES

SUBHEADING: TREATMENT

Page 11, lines 21-22: Having been diagnosed, caregivers reported many challenges faced by patients in getting timely treatment due to equipment failures and inadequate supplies.

Page 12, line 14: Caregivers described more timely access at private hospitals
SUBHEADING: ACCESS

Page 14, line 11: Physical access to institutions was cited as an issue by some caregivers.

SUBHEADING: INTER-INSTITUTION COORDINATION

Page 15, line 6: Caregivers reported that patients referred from one facility to another often found themselves at the mercy of the host institution.

Page 16, lines 1-2: On the smaller island of Tobago, this caregiver reported even greater logistical challenges in accessing specialist medical care.

SUB-THEME MEDICAL AND NURSING CARE

SUBHEADING: SYMPTOM MANAGEMENT

Page 17, lines 9-10: Caregivers described health professionals who seemed reluctant to prescribe opioids, delayed administration until late and utilized ineffective dosages.

Page 18, lines 1-2: Many caregivers reported more than three admissions in the last year of life.

SUBHEADING: ATTITUDES

Page 18, line 8-10: These caregivers described a lack of empathy, rigidly enforced hospital regulations and insensitivity to patient need.

MINOR THEME COMMUNITY

SUBTHEME: COMMUNITY PALLIATIVE CARE

Page 21, lines 17-19: In the limited situations where community palliative care or hospice admission was available, caregivers felt great relief as the burden of care was lifted.

SUBTHEME: SOCIAL SERVICES PROGRAMMES

Page 21, lines 23-24: For many of the caregivers surveyed, the delay in initiation of this service rendered it inaccessible.

Page 22, lines 11-12: Similar red tape was described as participants tried to access other government social services.
Social worker input and counselling were rarely available to the caregivers interviewed.

MINOR THEME: FAMILY UNIT

SUBTHEME: NEED FOR SUPPORT

Caregivers reported their struggles to care for the patient, with their own needs going largely unrecognized.

SUBTHEME: NEED TO ACT AS ADVOCATE

In the face of systemic inefficiencies, caregivers were forced to act as patient advocates to ensure that the patient’s needs were met.

SUBTHEME: NEED FOR FINANCIAL HELP

Caregivers described the economic burden of ongoing care.

MINOR THEME SOCIETY

SUBTHEME WORLDVIEW

An unexpected finding reported by caregivers was that some staff at public institutions held a very negative attitude towards cancer patients.

REVIEWER 2

1. General comments: the authors could consider reporting results of any correlation with type of cancer, who the caregiver was and any other information about the patient and caregiver that was collected.

Amendments made to comply with this were as follows:

RESULTS SECTION

MAJOR THEME INSTITUTIONS

SUBTHEME GENERAL SERVICES
SUBHEADING: DIAGNOSIS

Page 10, lines 24-25. The cancers with the longest delays in diagnosis were reported: The longest diagnostic delays were seen for patients with cancer of oesophagus (2), maxillary antrum, breast and lung).

Details were included about the caregiver speaking the utterance and relevant circumstances of the patient:

Page 11, lines 5-6: For these two widows whose husbands were diagnosed with oesophageal and colorectal carcinomas respectively, time to diagnosis was in the region of one year.

SUBHEADING: TREATMENT

Page 12, lines 1-2: The daughter of a 54-year old with lung cancer, who had already waited six months before being diagnosed, recalled:

Page 12, lines 7-8: For a 47-year old with advanced rectal cancer, the delay was in getting a nephrostomy tube inserted.

Page 12, lines 15-17: This son, caring for his elderly father, sought medical attention first at the public hospital but the long waits and unpleasant conditions eventually led him to seek private health care.

SUBHEADING: EMERGENCY CARE

Page 13, lines 12-14: This widow recalls waiting with her husband who had been transferred from another hospital but still needed to go through the emergency room process:

Page 13, lines 19-20: The son of a 90-year old described their visits to the emergency room during his father’s illness:

SUBHEADING: ACCESS

Page 14, lines 4-6: One widow who lived more than two hours’ drive from the general hospital, recounted the challenge of spending time with her blind husband.

Page 14, lines 17-18: This daughter described the process of transporting her mother to hospice for admission:

SUBTHEME MEDICAL AND NURSING CARE
SUBHEADING: COMMUNICATION

Page 18, line 24 and page 19, lines 1-2: These widows, the first elderly and poorly educated and the second, middle-aged and fairly well-educated, described similar issues.

Page 19, lines 12-13: The daughter of a patient with advanced prostate cancer found the doctors reluctant to discuss prognosis.

Page 19, lines 20-21: When conversations did occur, communication skills were deficient, as one participant, who had attained education only up to a primary school level, explained.

Page 20, Lines 5-7: The wife of this 43-year old with Stage 4 lung cancer described standing helplessly by, unable to meet with the doctors as her husband was put through what she recognized as futile treatment.

Page 20, lines 14-15: Another caregiver reported her 67-year old father with prostate cancer taking treatment cessation decisions into his own hands.

MINOR THEME COMMUNITY

SUBTHEME: COMMUNITY PALLIATIVE CARE

Page 21, lines 2-4: This 39-year old widow described her husband’s reaction to being told he would be taken home. He had spent many of the 20 months between onset of illness and death in and out of medical institutions.

MINOR THEME: THE FAMILY UNIT

SUBTHEME: NEED FOR SUPPORT

Page 23, lines 21-22: This participant struggled with caring for a toddler and an ill husband. The additional pressure of in-laws blaming her for her husband’s illness led her to despair.

Page 24, lines 1-2: The only daughter of this patient described how difficult it was to multitask and still be attentive to her father’s emotional needs.

MINOR THEME SOCIETY

SUBTHEME: WORLDVIEW

Page 26, lines 11-13: The narratives revealed culturally ingrained belief systems around alternative medical practices and beliefs in obeah/witchcraft. These beliefs were noted to be held by participants of lower educational levels.
Page 27, lines 1-3: Misconceptions and stigma around hospice care and morphine use were revealed. These misconceptions seemed to be quite widely held, expressed by participants of varying educational background.

2. A potential concern is the bias listed for the first author under limitations.

Response: The first author did not let the bias of sympathy for the caregiver impact her analysis or interpretation of these results. The statement of author bias previously on page 32, line 29, was therefore omitted as suggested.

REQUESTED REVISIONS

1. The caregiver point of view should be stressed throughout.

RESPONSE: This was revision was also requested by the first reviewer. Amendment are listed in section 4 above.

2. Address why caregivers of recently deceased patients were used as subjects and why this would be important i.e. why the caregiver perspective is important and why we need to listen to the caregiver viewpoint to influence change. It wasn’t exactly clear why patients themselves weren’t used as subjects.

RESPONSE:

These concerns were addressed in the METHODS section sub-heading STUDY DESIGN, Page 7, lines 1-18: A phenomenological approach was adopted with proxies selected as the source of data. Direct patient interviews would have been preferable, but the fragility of the palliative patient population makes this challenging (47-49) with up to 35% of the terminally ill study population unable to be interviewed (46). This high attrition rate is attributed to participants becoming more unwell or passing away during the study (50, 51). As patients deteriorate, the ethics of imposing the researcher’s demands at such a sensitive time also needs to be considered. Proxy interviews were therefore selected as the next best option for exploring the patient experience.

Despite the inherent limitations, the views of proxies are considered to have inherent value (52), as they form a key part of the unit of care. The proxy utilized here was the primary caregiver of the deceased. The caregiver plays a pivotal role at the end-of-life as an essential part of the health care team, often at significant personal cost (22, 53), while off-setting wider economic cost (54, 55). The patient’s achieving death at home is strongly influenced by his having a caregiver’s support (56, 57). The caregiver therefore directly impacts the patient’s end-of-life experience. Teno (58) suggested that our response as health care professionals to the voices of patients and families is perhaps the best outcome measure of the quality of our care. This study gives voice to some family caregivers.
MINOR EDITS

TITLE

The title was re-worked as suggested to read “Unmet needs of patients with cancer in their last year of life as described by caregivers in a developing world setting: A qualitative study.”

ABSTRACT

Please be clear whose needs this study is addressing (patients or caregivers or both).

RESPONSE: The study’s aim was to address the needs of the patients. Amendments were made to the ABSTRACT, Page 2, lines 3-6: We set out to explore the lived experiences of families and caregivers of recently deceased cancer patients in Trinidad and Tobago and to determine the unmet needs of the patients and what recommendations could be derived to improve the current services.

SPACING: The spacing between words and reference numbers in the text was checked and made consistent.

METHODS

Please clarify why 6-12 months was used and not less than 6 months

RESPONSE: This was explained as follows on Page 7, lines 19-24, and page 8, lines 1-3.

Evidence is lacking for an ideal time frame for after-death interviews (47-49, 59). While interviewing soon after an incident is likely to yield more accurate results, the challenge lies in being sensitive to the needs of the grieving family and of interviewing before recall bias is an issue (48). In this study, interviews were conducted 6-12 months after death in the hope that a culturally acceptable period of mourning would have elapsed, yet recall would still be accurate. Some researchers suggest that an acceptable approach may be leaving it to the participant to say if the timing is right (48, 60). In this study, only one participant declined because of the perceived emotional burden, lending support to the 6-12 month time frame chosen.

RESULTS

Clarify why only 15 participants and not 18 were interviewed.

This was explained in the METHODS section, SUB-HEADING RESULTS, Page 9, lines 18-22.

RESPONSE:
Twenty-one interviewees were eligible but three were unavailable for interview and three others declined for reasons of health and emotional distress. This left fifteen available to be interviewed.

REFERENCES: These were reviewed and the capitalization made consistent.

LIMITATIONS: The statement of intention originally on page 32 line 22 was removed as recommended.

REFERENCES

Changes in the format of references and new references are displayed highlighted.

THE FOLLOWING ADDITIONS AND AMENDMENTS WERE MADE TO MEET COREQ CRITERIA

Credentials: inserted on Page 1, lines 6 and 16.

Occupation and gender: Page 8, lines 15-17: Participants were contacted by telephone by KCS who introduced herself as a general practitioner with an interest in community palliative care.

Experience and training: Page 6, lines 12-14: The researcher KCS had a background in general practice with a special interest in community palliative care

Relationship established: Page 8, line 8-9: There was no prior relationship between researcher and participants.

Participant knowledge of interviewer: Page 8, lines 16-17: Participants were contacted by telephone by KCS who introduced herself as a general practitioner and explained the intended aim of the study: to identify the unmet needs of cancer patients in their last year of life.

Interviewer characteristics: Page 6, lines 12-14: The researcher KCS had a background in general practice with a special interest in community palliative care.

Presence of non-participants: Page 8, line 20-21: Interviews were conducted by KCS, with only participant and interviewer present.

Interview guide: Page 8, lines 21-22: The semi-structured interview questionnaire (see Appendix 2) was employed after being first pilot tested.

Repeat interviews: Page 9, line 22: One repeat interview was required.
Field notes: Page 8, line 23: Interviews were audio-recorded and field notes made during and after interviews.

Duration: Page 10, line 2: Interviews lasted between one and two hours.

Number of data coders: Page 9, lines 2-4: As both authors were of primary care backgrounds, a third coder and research assistant with a social science and education background was recruited, to lend diversity and a different perspective.

Description of the coding tree: Page 9, lines 8-11: Two coders then re-read the material, individually identifying and coding all narratives that spoke to the research question. Codes were then shared, discussed and the emerging common themes identified. Finally, a thematic map was developed with the themes divided into major and minor ones.

Clarity of minor themes: Page 10, lines 10-11: Major themes: Institutions, Minor themes: Community, Family unit and Society. Major and minor themes and subthemes were stated at the start of each new section.

Thank you for the opportunity to re-submit.

Respectfully,

Karen Cox