Author’s response to reviews

Title: Palliative home parenteral nutrition in patients with ovarian cancer and malignant bowel obstruction: experiences of women and family caregivers.

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Author’s response to reviews:

Dear Dr Gummlich

Please find our comments in response to Dr Moreno-Villares.

We thank Dr Moreno-Villares for commenting that our study would be of interest to the readers of BMC Palliative care.

1. Minor comments: line 28 "is a problem IN advanced cancer"; line 80: colon instead of point; 137: interviewer
The paper has been amended to include line 28 "is a problem IN advanced cancer"; line 80: colon instead of point. However, the word ‘interviewee’ at line 137 has been left unchanged as the interviewer was responding to the participant (i.e. the interviewee).

2. Mat & Met

   a. Data on the number of interviews differ in abstracts from those in the text (20 women and 13 family caregivers vs 20 women and 15)

13 family members were interviewed not 15 – this mistake was found and corrected when the paper was transferred to BMC Palliative Care.

   b. Please, describe how HPN is infused at home (overnight, all day, etc), as well as if there are other medications that need to be infused. Also, how long was since the initial diagnosis was done and total number of surgeries (in table 1 it is the type of surgeries but not if they were done in the same procedure or in a different one)

We have clarified (at line 114-115) that PN is administered overnight and no medication is given by the central line. The median time from initial diagnosis of ovarian cancer and bowel obstruction (27.5 months range 1-184 months) has been added at line 182-184.

The information on type of surgery was included to give some background information on the patients. Given that the surgeries were not performed at the oncology hospital it was only possible to collect data on type of surgeries not whether they were performed at the same procedure or different procedures. This has been highlighted as a limitation in the discussion (lines 516-519).

   c. Please, include which are the criteria to consider "inoperable MPO" and how the decision to send the patient home is taken

The criteria for inoperable MBO was review of appropriate imaging by an oncological radiologist with extensive experience of the management of ovarian cancer. Findings considered inoperable included multilevel obstruction, extensive serosal disease with no transition point, extensive mesenteric disease which would prevent bowel mobilisation. In cases where there was doubt about operability a gastrointestinal surgical consultation took place. This has been clarified at lines 104-109. Home discharge took place when, the patients symptoms secondary to bowel obstruction were adequately controlled, there was satisfactory fluid and electrolyte balance with an established PN prescription, the patient’s performance status was stable and any recommended home care package was in place. This has been clarified at lines 117 to 120.

   d. Line 135: table 1 has no information on the number of interviews.

Line 135: table 1 has been corrected to table 3 which gives information on the number of interviews.

3. Results
a. Results should be provided only for those 26 in whom HPN was considered, and interviewed, as PN is an standard of care in obstructive patients.

An important strength of this paper is that it gives information on the whole cohort of 38 women who were in malignant bowel obstruction during the study period. We were keen to show the patient characteristics and nutritional status of those who were interviewed and those who were not. This is to provide transparency to the reader and to avoid selection bias. Survival data are given broken down into clinical categories so that those who got and did not get parenteral nutrition can be seen.

b. Some information on the need to attend the ER, readmitted, rate of complications is needed.

Information has been given on line infections (lines 187-188) as this is one of the major PN related complications that this group of patients is likely to encounter. Some of the patients were admitted with non-PN complications. However, this information is likely to be an underestimate as the project was being conducted at a tertiary referral centre and patients could have been admitted to a local hospital for cancer related issues; given this and as it is not related to PN this information has not been included. This had been highlighted as a limitation in the discussion (line 519-521).

c. In my experience, one on the most challenging aspects is when to stop HPN in this type of patients and should be agreed prior to discharge. Please, describe.

We would agree that one of the most challenging aspects is when to stop PN in these patients. However, the aim of the paper was to understand the experience of PN from the patient and family perspective. Therefore during the interviews the question of whether the patients had ever thought about stopping was put to the patients and their answers recorded. However, we have added in some information about how oncologists may mention stopping in a general way to patients (lines 396-398), but no patients mentioned this was discussed with them at interview. One patient commented that a doctor at the intestinal failure unit asked her to think about what she wanted to do in the case of her developing sepsis and so she thought about stopping in this instance. This has been clarified in the paper (lines 404-406).

d. Some comments on the performance status must be done in this section (there is a partial reference in the Discussion, line 443)

Performance status in addition to being given in table 1 is discussed at lines 181 to 183.

e. Figure 2 is not referred in the text

Figure 2 is referred to at line 201

4. References
Please complete according to Instruction for authors. Ref 4, 7, 28, 31 are incomplete.

Ref 4, 7, 28, 31 have been checked and amended.

Please find our comments in response to Dr Vashi.

We thank Dr Vashi for commenting that our study was well thought out and addressed the challenges faced by patients and family members on HPN

1. What is the time frame of the CT derived sarcopenia score and the discharge date?

The mean time from CT scan date and date of discharge (53.4 days SD ±63.9) has been added (line 195-196). However, we have not claimed to give a sarcopenia score as CT scans can only identify low muscle mass rather than sarcopenia which requires an addition measure of functional status.

2. I did not see any survival data in the two groups. Did the patients who were interviewed have better QOL or better acceptance of HPN compared to the ones who did not?

3. Incorporating any data on the differences in the two groups will make the article more robust.

Tables 1 and 2 were included to show that overall there was no difference between those patients who were interviewed and those who were not at the time of admission with bowel obstruction. However, when presenting survival data we chose to present survival of women in a similar clinical situation. Therefore, we provided survival data for the whole cohort of 38 women in bowel obstruction, the 32 women who received parenteral nutrition, the 6 women who did not receive parenteral nutrition as well as the 17 patients who had home parenteral nutrition. We also provided figure 2 which compared the survival of those who received parenteral nutrition in hospital to those women who had parenteral nutrition in hospital and at home. Women who were not interviewed could be found in all categories i.e. not receiving parenteral nutrition, parenteral nutrition in hospital only and parenteral nutrition in hospital and at home.

Given the research methodology of interviewing patients, it is impossible to know if patients who were not interviewed had a better quality of life or acceptance of home parenteral nutrition compared to those who did not. However, in the cohort presented in the paper only 2 women went home on parenteral nutrition and did not agree to be interviewed.

Kind regards

Anne Marie Sowerbutts on behalf of the research team