Author’s response to reviews

Title: Integrated respiratory and palliative care leads to high levels of satisfaction: a survey of patients and carers

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Author’s response to reviews:

Dear editors and reviewers

Thank you for the opportunity to submit a revision for our manuscript entitled “Integrated respiratory and palliative care leads to high levels of satisfaction: a survey of patients and carers”. Thank you also for the thoughtful and constructive feedback, which has enabled us to revise and improve the manuscript. We have addressed each reviewer’s specific comments and will now highlight the detailed changes made.

Reviewer 1 comments

We do apologise that the survey questionnaire was not available. There seems to have been an issue when the files were uploaded. The survey questionnaire was subsequently supplied after submission (as requested by reviewer 3) and is now available with the remainder of the submission.

As requested the first sentence of paragraph 3 (page 4) in the introduction has been changed to remove the word “demonstrated”. This sentence now reads:
“The Advanced Lung Disease Service (ALDS) in Australia is one such model and has been shown to be associated with improved outcomes including enhanced active management of breathlessness, increased advance care planning, greater access to palliative and end of life care and reduced unscheduled healthcare utilisation.”

Reviewer one has written: “The third stated aim of the study was to determine priorities for service development. It was not clear how this aim was explored in the survey.”

Our response: There were three questions (questions 24-26) in the survey under the section “How can we improve” that specifically asked patients about which other health professionals they would like to see; if there was any other help or support they would like to receive from the ALDS team or anything the ALDS could do better; and regarding any other comments they had about the ALDS. These three questions together were used to understand priorities for future service development. Sections related to service development have been added to the result (page 11) and discussion (page 15).

Participants were given a choice of how they would prefer to complete the survey and were informed of these different options (in a letter than accompanied the survey) when the postal survey was sent to them. Page 7, paragraph 1 (survey distribution) has been altered to make this clearer:

“Patients and carers were given the choice of completing the survey questionnaire by post, or at a hospital outpatient appointment where they could either complete the paper questionnaire independently, or as a face-to-face, structured interview with a researcher (TM) who was independent of the ALDS clinical team. Patients and carers who completed the survey by interview, were spoken to separately where possible. Paper copies of the questionnaire (as well as a separate letter explaining the options for completing the survey) were posted to all current ALDS patients, then if not returned, four weeks later each patient was telephoned by the independent researcher to remind them of the different options for survey completion.”

As requested details regarding how many questionnaires were completed by each survey distribution method have been added to the results section (paragraph 1, page 8):

“Of the participants, thirty-nine (60.9%) patients and 11 (45.8%) carers completed the questionnaire as individual, face-to-face interviews in clinic and 25 (39.1%) patients and 13 (54.2%) carers returned the survey by post.”
As requested, the length of time that patients had been cared for by the ALDS has been added to paragraph 1 (page 8) of the results:

“Patients had attended a median of eight (IQR= 4-12) ALDS appointments over a median time period of 21.3 (IQR=8.4 - 36.9) months.”

A table legend has been added (as noted below) beneath Table 2 indicating that the quotes provided are examples not the whole extent of free text comments related to each theme:

“Examples of some of the illustrative quotes provided by participants are included.”

Information on how many of the participants were experiencing each of the symptoms listed was only routinely collected for breathlessness and mood disorders, but not the other symptoms. This available information has been added to paragraph 1, page 10 of the results:

“Sixty (93.8%) patients reported receiving help managing breathlessness, with 59 (92.2%) patients documented by the medical team as having severe breathlessness (mMRC=3-4) and 5 (7.8%) having moderate breathlessness (mMRC=2). Similarly, twenty-five (39.1%) patients reported receiving help with mood problems, with 29 (45.3%) known to have a medically confirmed diagnosis of anxiety and/or depression.”

The question about feeling more confident managing symptoms referred to all the listed symptoms, not each individually. While it would have been helpful to have more detailed information regarding confidence managing each separate symptom, when designing the survey we needed to balance the number of questions against the time taken to complete the survey (and thus burden imposed on participants).

The findings in this survey and how they compare with patients surveys from other holistic, integrated services (CBIS, BSS, INSPIRED) is outlined in the discussion paragraph 2, page 12 (see below). Additionally description regarding the different models of care offered by those other integrated services and how they compare to the ALDs is reported throughout the discussion

“Respiratory patients managed by two holistic breathlessness services (the London Breathlessness Support Service (UK) and Cambridge Breathlessness Intervention Service (UK)), as well as patients managed by the Canadian integrated respiratory and palliative care service
“INSPIRED” have also reported high levels of satisfaction and greatly valued similar aspects of care 17-19.”

Participants were not asked any specific questions regarding their perceptions of the relationship between the primary care team and the ALDS. As highlighted in the ERJ Open research paper, which is referenced in this manuscript, the ALDS strives to support clinicians working in primary care to manage patients with advanced respiratory disease. The purpose of the statement in the discussion (paragraph 1 page 12 – see below) is to highlight the need to collaborate with primary care teams to ensure new integrated services respond to local health needs and are sustainable and flexible (i.e. there is not one right model).

“However, while longer term interventions, which offer continuity of care, may be preferred by patients and their carers, integrated respiratory and palliative care services must be accessible and sustainable. Therefore close working relationships with primary care and other community health teams, together with flexibility to accept referrals promptly in response to individuals’ changing health are essential.”

The question regarding which other health professionals the participants wanted to see in the ALDS, was a multiple choice question in which as many options as desired could be selected. Participants were not asked to specify why they wanted to see any other health professionals. Again the survey questionnaire needed to balance the desire for information against total number of questions asked. The discussion regarding patients finding clinic appointments exhausting is well noted in the literature, particularly for patients who are too breathless to leave the house. This has been made clearer in the discussion, paragraph one, page 15:

“Furthermore, though patients with advanced lung disease desire longer consultations to discuss their health, attending medical appointments can be challenging due to breathlessness 27, 28. Therefore integrated care clinic visits, which enable patients and carers to see two or three health professionals together over an hour, while efficient may be exhausting for patients. Consequently, home visits may overcome patients’ unwillingness to see multiple health professionals during “one stop” clinic visits.”

Reviewer one wrote: “Again related to the stated 3rd aim of priorities for service development: given the data from this survey, do the authors see the "physician" role in an advanced lung disease service could be taken on by either: a respiratory care physician with extra palliative care training; or a palliative care physician with an interest and expertise in respiratory end of life
care)? ie it could be either/or? The conclusion seems to indicate the authors suggest the former option.”

Our response: Respectfully we disagree that our conclusion suggests that we only believe respiratory physicians should fulfil the “physician” role within an integrated service. Indeed the fourth paragraph of the discussion (on page 14) makes it clear that we feel both respiratory and palliative medicine physicians are important members of integrated respiratory and palliative care services. Furthermore the second sentence of the conclusion actually indicates that patients need access to “palliative care activities”. The importance of who provides them depends on what local services are available in each region. Palliative care services are not widely available in all countries, nor in all regions (particularly in geographically vast countries like Australia), whereas respiratory services are more widespread. Therefore to suggest that only a palliative care physician can provide palliative care risks preventing many patients with advanced respiratory disease from accessing such care.

“Therefore core components of new integrated respiratory and palliative care services should ideally include: access to palliative care activities (but not necessarily palliative care personnel if the respiratory team can provide this care), health and self-management information and education, and home support.”

Reviewer 2 comments

The research interviews were structured, therefore the interviewer predominantly read out the questions verbatim. However, when asking open-ended questions (e.g. Do you have any other comments about the ALDS?), spontaneous unstructured discussion also occurred. This has been clarified in the first paragraph in page 7:

“Patients and carers were given the choice of completing the survey questionnaire by post, or at a hospital outpatient appointment where they could either complete the paper questionnaire independently, or as a face-to-face structured interview with a researcher (TM) who was independent of the ALDS clinical team.”

As discussed in response to the comments from reviewer one earlier, the information regarding how many questionnaires were completed by each method has been added to the results section (paragraph 2, page 8).
The responses from the final three survey questions regarding service development have been moved to sit together in a new final section entitled “service development” within the results (page 11). Similarly a corresponding section has been added to the discussion (page 15).

In this study information regarding the frequency of each symptom was collected (from routine information in the ALDS clinical notes) for the symptoms of breathlessness and mood disturbance. This collateral information demonstrated that nearly all patients reporting those symptoms received specific support to address them from the ALDS. As discussed in response to the comments from reviewer one, this information has been added to paragraph 1, page 10 of the results. Information regarding cough, sleep, appetite, nausea/vomiting and bowel habit is also routinely collected in the clinic but was not audited to compare against the patients recalled experiences, as this study mainly focused on the patients experiences. Therefore it is not possible to comment on whether the service is addressing those symptoms adequately or not i.e. if the patients who recalled having those symptoms actively managed were the only ones experiencing them (as shown with breathlessness and mood issues) or whether there were others who did not have them addressed. The lack of collateral information for some symptoms has been added to the limitations section of the discussion (paragraph 2, page 16):

“Surveys require participants to retrospectively recall in detail many aspects of their care that may be forgotten, particularly when receiving long-term care. Collateral data collected from the clinical notes demonstrated that the number of patients who informed the ALDS clinical team that they experienced severe breathlessness and mood disorders, and the number of patients who recalled receiving support for both issues were well matched. Collateral information regarding other symptoms (such as cough, sleep and appetite) would have strengthened this study and identified any gaps in symptom management.”

Reviewer 2 wrote: “Nearly a third of carers stated a preference for written resources. I am not clear if any resources are currently provided within the service?”

Our response: All patients and any carers who accompany them to the clinic or who are present during home visits are provided with written resources from the ALDS. This has been clarified by adding the following sentence to paragraph 1 of the methods section (page 5).

“The service is a partnership between respiratory and palliative medicine and focuses on active symptom management, individualised patient and carer education (including providing written resources), and advance care planning.”
Reviewer 3 comments

As requested the percent (response rate) for carers has been added to the abstract:

“Eighty-eight responses were received from 64 (80.0%) eligible patients and from 24 (60%) eligible carers.”

As discussed in response to the comments from reviewer one earlier, the first sentence of paragraph 3 (page 4) in the introduction has been changed to remove the word “demonstrated”, with the word “associated” used instead.

The final paragraph of the introduction (page 5) has been amended to explicitly identify gaps in the current evidence base regarding patients’ experiences of integrated services.

“Patients’ experiences and satisfaction are central in the assessment of healthcare quality, however, little is known regarding patients’ or carers’ attitudes to new models of integrated respiratory and palliative care. This study aimed to assess patients’ and carers’ experiences of the ALDS, identify valued aspects of the service and determine priorities for service development.”

Further information regarding the ALDS has been added to the first paragraph of the methods section (pages 7-8):

“The Advanced Lung Disease Service (ALDS) is a multidisciplinary, single point-of-access, integrated respiratory and palliative care service, based within a major Australian teaching hospital. The service is a partnership between respiratory and palliative medicine and focuses on active symptom management, individualised patient and carer education (including providing written resources), and advance care planning. The ALDS accepts all referrals for patients with severe, non-malignant, respiratory disease, with no set referral criteria. Either long-term care (over the last few years of life) shared with the primary care team or short-term care, are offered. Patients and any accompanying carers are usually seen together (unless they request to be seen separately) in the ALDS clinic, where all patients meet a respiratory physician and nurse specialist who both have expertise in palliative care, and the majority also meet a palliative care doctor. Home visits from the ALDS respiratory nurse specialist are also offered according to patients’ needs. Additionally, the ALDS provides support to manage psychological issues from a psychologist in the ALDS clinic, a nurse-led telephone support service, a regular multidisciplinary team meeting and case conferences with community health teams and primary care 16.”
As noted earlier, the survey questionnaire has been uploaded as a supplementary file. More detail has been added to the methods (paragraph 2, page 6) regarding survey question themes:

“Survey questions focussed on four main themes:

1. ALDS hospital clinic (including usefulness of clinic visits, symptom management, health information discussions and waiting time to be seen)

2. ALDS nursing support service (including types of telephone support accessed and home visits)

3. General views and overall opinion (including confidence in the service, feeling heard and respected, having enough time and opportunities to discuss important aspects of care, and valued elements of the service)

4. Areas for future improvement”

Further detail regarding the analysis of the free text comments has been added to the “data analysis” section of the methods on page 8:

“Free text comments were extracted and transcribed separately. TM analysed the comments using a descriptive and exploratory thematic analysis framework to identify themes until thematic saturation was reached. Both the free text comments and themes were reviewed (by NS and TM) and following discussion, refinement and consensus the final themes were agreed.”

Information regarding instances a dyad of carer and patient responded has been added to paragraph 1 of the results section, page 8:

“Forty-two surveys were completed by patients, without receiving responses from any eligible carers, and 2 responses were received from carers without receiving a completed questionnaire from the patient. Twenty-two patient and carer dyads participated (i.e. individual responses were received from both the patient and their carer).”

The median number of ALDS clinic visits was included in Table 1. However, the median number of clinic visits for patients and the time period this occurred over have been added to paragraph 1 (page 9) of the results:

“Patients had attended a median of eight (IQR= 4-12) ALDS appointments over a median time period of 21.3 (IQR=8.4 - 36.9) months.”
As requested, throughout the results, we have now indicated when findings are a summary of free text comments as opposed to pre-determined options.

In the last paragraph on ALDS clinic management (results section page 10) the missing percentage sign has been added.

The number and percentage has been added to the last sentence of the ALDS respiratory nursing service section (paragraph 1, page 11):

“One third of patient (34.4%) and carer (33.3%) participants recalled receiving a home visit from the ALDS specialist respiratory nurse, with most participants (95.6% of patients and 87.8% of carers) who accessed this service regarding this as helpful.”

The wording “a large number of participants” has been removed from paragraph 1 of the discussion (page 12). This sentence now reads:

“In this study, which had a very high response rate and is the first structured survey to include carers receiving support from an integrated respiratory and palliative care service, participants reported a very, high level of satisfaction with three quarters rating their care as excellent, nearly all recommending the ALDS to others and all participants finding the ALDS helpful.”

The reference has been added to the sentence at the end of paragraph four of the discussion (page 14).

Whilst we agree that the cost implications of home visits are important when considering new models of care, this research study was a survey. Therefore cost implications were not directly considered in this study. As such we respectfully do not feel this is relevant to the discussion in this manuscript.

As requested, the following sentences have been added to the limitations section (page 16):

“However, neither the questionnaire used in the study nor the one used be Reilly et al (from which this survey questionnaire was developed) have been validated 17.”

“While a minority of eligible patients (six) were excluded because they did not speak English, it is unclear how patients from non-English speaking backgrounds view the ALDS.”
The conclusion has been amended to remove results from the previous study on the ALDS, and priorities for future research have been added.

“Integrated respiratory and palliative care provided by the Advanced Lung Disease Service is associated with very high levels of patient and carer satisfaction. Continuity of care, high quality communication and feeling cared for were greatly valued and highlight simple but important aspects of care. Therefore core components of new integrated respiratory and palliative care services should ideally include: access to palliative care activities (but not necessarily palliative care personnel if the respiratory team can provide this care), health and self-management information and education, and home support. Importantly, multi-site controlled trials are still required to examine on a larger scale the effectiveness (including cost-effectiveness) of integrated palliative care for patients with advanced respiratory disease, as well as further studies to understand patients’ and carers’ perspectives regarding these new models of care.”

Thank you again for the opportunity to revise and improve our manuscript. We look forward to hearing your decision regarding publication.

With very best wishes

Dr Natasha Smallwood