Author's response to reviews

Title: Factors associated with multiple transitions in care during the end of life following enrollment in a comprehensive palliative care program

Authors:

Beverley Lawson (bev.lawson@dal.ca)
Frederick I Burge (fred.burge@dal.ca)
Patrick Critchley (pcritchley@tadh.com)
Paul McIntyre (paul.mcintyre@cdha.nshealth.ca)

Version: 2 Date: 4 April 2006

Author's response to reviews: see over
March 31, 2006

Editors
BioMed Central

Dear Editors:

Re: Factors associated with multiple transitions in care during the end of life following enrollment in a comprehensive palliative care program (man_id=1182750610903534)

Please find attached our revised manuscript entitled as above. Below we address each reviewer’s comments by including their concern in bold text first, followed by our response. Changes in the manuscript are referred to by Section heading, page, paragraph and if applicable, line numbers.

Thank you again for your consideration of our manuscript.

Yours sincerely,

Beverley J Lawson, MSc
Research Associate

Response to reviewers

Reviewer 1
Dated January 30, 2006 (LJK)

No major or minor revisions were suggested.

Reviewer 2
Dated February 3, 2006 (APA)

Major Revisions
Reviewer 2, Major comment 1: “The authors do not provide any information about the data quality of the PCP database. Hence, it is difficult to evaluate the merit of the findings. Who is entering data? What training have they had? How confident are we that the people entering data know the correct diagnosis, location of care etc. What is the frequency of missing data? Are there double data entry? Does the database have background validation measures? What is the security and are data de-identified before analyses? Did the IRB or Ethics Committee approve this analysis? In other words, how can we be sure that the database reported here is complete, reliable represents transitions as the authors define them, and maintains the integrity of patient confidentiality?”
Response 1: The PCP database is a hospital administrative database where information is entered from a patient’s chart by a trained data entry clerk whose sole function is to ensure the completeness and integrity of the information. Chart information is collected by the nurse who does the initial assessment and updated by the nurses caring for the patient. A patient will remain on a particular nurse’s ‘care list’ until updates are made. Therefore, nurses tend to report changes (or transitions in care) immediately.

On the database, fields such as diagnosis, reason for referral, service, location etc are all table driven. That is, there is a defined list from which the entry is picked, therefore avoiding mis-typings and ‘uncodable’ entries. Similarly, entries are automatically validated against other data, where possible, to force logical linkages (a patient being cared for by the home support service cannot be entered as being in the hospital at the same time). All fields amenable to making a forced data entry in a particular format are done so (e.g. dates, chart numbers). Where feasible, fields are made mandatory to force data entry. In cases where mandatory entry doesn’t work (such as diagnosis) a series of reports are generated at intervals identifying what information is missing. Collection of this missing information is immediately sought to complete the record. Thus, missing values tend to be low in the PCP database. For instance, during the years of this study (1998 to 2002), age was missing from 0.5% of records, only one record did not have the place of death recorded, 1% were missing a diagnosis on the record. Death information is validated against provincial vital statistics death information which is received weekly. Given these measures we are confident that the CDHA PCP database is as valid and reliable or perhaps better than any other hospital administrative database where entry is controlled.

With respect to data security and patient confidentiality, data received for analysis do not contain personal identifiers (e.g. names, addresses, health card numbers, chart numbers). In order to link the patient information to transition data an encrypted identification number was created. Only the individual controlling the database who ultimately extracted the information and the analyst of this project (BL) have access to the encrypted files which are housed on a secure server. Research ethics approval was provided for this project from the Capital District Health Authority research ethics board and is noted in the article under the Method, Data section.

To address the reviewer’s concern we have added some additional information about data entry and measures taken to ensure patient confidentiality under Methods, Data, page 6, paragraph 1 and Methods, Data, page 7, last line of the second paragraph.

Reviewer 2, Major comment 2: “The authors do not present any evidence that transitions cause distress? Further, they define transitions as a change in location or a change in service. Why this definition, and how is it causally related to distress? The most obvious concern is the definition of distress being defined by change in care from PCP to NSCC – is this necessarily a bad thing?”

Response 2: We agree with this reviewer that there is little evidence in the literature that transitions cause distress. We searched quite thoroughly for this literature and found little. However, in our own clinical work with this population and in our shared research work with the clinical palliative care program and cancer centre we know that transitions are a point of stress
for patients and families. Physical moves from home to hospital and vice versa are particularly stressful times. This is often because such moves are fraught with meaning of impending mortality: “My disease is worsening and my next move will be to the hospital to die” or “They (the health professionals) think my dying wife is stable enough to be at home but I have no idea how I will cope with her medications and dressings and the stress on my kids who are living at home”. Transitions where new health professionals become involved (service transitions) are also stressful as patients and families have to re-tell their story and perhaps re-negotiate their personal goals of care.

At the same time we acknowledge that transitions may also be quite welcomed by patients and families. When the stress of symptoms or caregiving situations is too much at home, a move to hospital may be a relief to all. The same may be true of a transition of service provider such that patients may see the most competent professionals needed are finally involved in their care.

Nevertheless, in our modern health care systems we must ensure that care that moves patients across care settings and across clinical programs is as integrated and as smooth as possible.

We have added to the description of the background section of our manuscript to better set this stage (Page 4, paragraph 1; page 4, paragraph 2, line 1).

Reviewer 2, Major comment 3: “In reviewing results, there are the different transition periods and then the associated predictors for each transition. It started to get confusing how they all lined up, especially given the multiple levels of each characteristic in the model. A figure with predictors at each time point including similarities and differences would be useful. This figure should also include a representation of the mean/median number of transitions in each of these periods.”

Response 3: This is a very good idea. We have created a table to summarize our results (Table 4) and refer to it in the text (Results, page 12, paragraph 2). Although a figure was suggested, we were not able to create one that captured all required elements.

Reviewer 2, Major comment 4: “What about the influence of local effects? For example, might the differences found for women really reflect local culture, health system issues and norms? Is this really generalizable? In fact, much of the discussion points to the importance of various factors that are really local issues and not necessarily applicable outside of the PCP catchment area. How should readers interpret these? How should they apply this new knowledge more broadly?”

Response 4: Although we agree there are likely “local effect” influences, we actually feel that the factors pursued in the discussion are indeed ones that are generalizable in nature. The fact that women and the elderly make fewer transitions is important for all palliative care service providers to know. I do not feel we are unique in how our local palliative care program is structured nor are the services available more generally to this group of patients unique. We can only hypothesize as we did in the discussion what might be behind the fewer number of
transitions for these groups and the reader will need to consider how those same groups are cared for in their setting. We believe it would be worthwhile to do qualitative research to see if we can understand why these results are the way they are.

Other factors we have discussed include the availability of home care services, hospital beds and the distribution of diseases (cancer types, non-cancer causes of death). All of these factors are common issues nationally and internationally in the health service delivery systems of developed countries. Many countries have experimented with reducing numbers of acute care hospital beds, expanded home care programs and disease-specific care programs.

The discussion of these factors, we believe, actually enhances the generalizability of our findings.

### Minor Revisions

**Reviewer 2, Minor comment 1:** “Abstract – Background sentence #1 suggests that this paper might be about home caregivers, but in fact it is about clinical caregiving. This sentence should be reworded so that the correct context is set.”

Response 1: Agreed. We have edited that sentence to read, “Patients often experience changes or transitions in where and from whom they receive professional health services at the end of life.”

**Reviewer 2, Minor comment 2:** “Writing style – long sentences that need to be broken up with periods, no commas. This is especially noticeable in the background section.”

Response 2: We have edited the style in the background to shorten the sentences.

**Reviewer 2, Minor comment 3:** “PCP – What is the length of stay, # of referrals per year, % cancer for PCP. This information should be noted in the methods section.”

Response 3: In total, 4434 patients were admitted (referred) to the PCP (mean 887, standard deviation 38). Admissions to the program remained relatively stable over the 5 years study period with no evident trends in variability. Over 90% of patients admitted had a cancer diagnosis. This information has been added in the Methods section, Data, Page 6, Paragraph 1, Lines 2 and 3. However, median length of stay among patients is provided in detail in a previous publication and is dependent on whether the patient was receiving ‘active’ or ‘non-active’ care and the location of care (Burge F, Lawson B, Critchley P, Maxwell D: Transitions in care during the end of life: Changes experienced following enrollment in a comprehensive palliative care program. *BMC Palliative Care* 2005, 4). As noted in this article, ‘active’ care is defined as care provided to a patient by PCP staff; ‘non-active’ care refers to care being provided by individuals or others not associated with the PCP program. We do not feel this information and the details associated should be repeated here and is not included.
Reviewer 2, Minor comment 4: “How did this population look in comparison to all patients referred and admitted to the PCP? What proportion did this population represent (were there missing data? Were some groups eliminated?)? How closely does the PCP population pre-2002 represent their population now?

Response 4: As noted we included ALL patients who were registered and who had died within the study period (January 1998 to December 31, 2002). No groups of patients were excluded from the data. Deceased patients represent 90% of admissions during this time frame. The majority of patients who had not died were admitted during the final year of the study (2002) and were still being followed by the program.

As previously noted (Major revisions, response 1), missing data are minimal from the PCP database.

Admissions to the PCP substantially increased in 1997 as noted in the Background, paragraph 2. Further increases were also evident in 1998. Between 1998 and 2002 (and again in 2003) admissions remained relatively stable. How similar is this today’s group of patients to pre-2002? Admissions to the program in 2003 are similar to those from 1998-2002. Admissions in 2004 indicate numbers may be on the rise but additional years are required before we can say this represents a trend. Patient characteristics have not been examined for the years beyond 2002.

Reviewer 3
Dated March 8, 2006 (IJH)

Reviewer 3, Comment 1: “This paper appears to be a further publication from the stable of work published by the group, building from the interesting and valuable paper they published in BMC Palliative Care in 2005;4:3. There are some areas of overlap with this already published paper, particularly in the methods, results – see for example table 1 and figure 1 – and even within the background and discussion (e.g. points about transitions being stressful/causing anxiety). The authors need to remove the overlaps as readers will not wish to read the same information twice. They should also acknowledge the prior publication of their work in BMC Palliative Care, and give reference to that.”

Response 1: Yes, we agree that there is some overlap with respect to the methods and descriptive results of our previous paper. The database used for this analysis was the same examined in the initial paper. Therefore it is hard to avoid the overlap with respect to methods (especially) and the description of the subjects and dependent variable of interest, total transitions.

Although we had referenced our past work in the results section, an additional paragraph has been included in the revised manuscript immediately under the Methods heading (page 5) which states this is a ‘further’ investigation with the appropriate reference. There are some common elements to the background of this paper and the previous BMC one, but once again we feel they are mostly unavoidable. We have also added a citation to our previous work in the background section, alerting the reader to the companion article (Background, page 5, paragraph 3).
It is true that Table 1 and Figure 1 are very similar to those previously published. However, we feel it is important to provide a complete description of subject characteristics and transition numbers given they are a key variables in this analysis. We therefore decided to retain Table 1 (Characteristics of patients) in the article as it stands for immediate access to the reader. However, Figure 1 which illustrates the total number of transitions experienced was removed and a complete description provided in the text.

In summary, we realize there are overlaps and this has been one of the main reasons to put both papers in the same journal so that the reader can locate them both easily and there are not issues of copyright duplication.

Reviewer 3, Comment 2: “The main new material in this paper appears to be the analysis of factors associated with transitions for patients within the palliative care service. For this a limited number of factors were associated with increased transitions.

Some factors that the authors need to consider in greater depth are:

Data source. They included only those patients who were in receipt of palliative care services in their area, and therefore the results are not likely to be generalizable to other groups. Also the team may have acted to reduce transitions.”

Response 2: We are not sure why patients in our area would be considered as significantly different from end of life patients enrolled in a comprehensive palliative care program in other Canadian provinces or other countries with similar programs and universal health care. Patients enrolled in the program are from the general population and referred through their family physician or at times specialist. We know of no specific actions aimed to reduce transitions that are not a part of the routine care of any palliative care team.

Reviewer 3, Comment 3: “How accurately were the number of transitions linked to the time period in care? Are the authors sure that the greater number of transitions for some patients was not because they cared for those patients longer?”

Response 3: We believe the number of transitions linked to the time period in care are accurate. Transitions or changes in provider or care service are recorded in the PCP database starting with the initial date of patient registration and continuing until death. Patients are assigned to case nurses. As changes occur, the nurse caring for the patient reports the change (date and location; service provision). If they do not, the patient will remain on their daily list of those they are responsible for (e.g. Patients in house; Patients on home support). It is probable that for a small proportion of patients, a lack of transitions is a reflection of being ‘lost to the system’. In other words, they registered with the program and a death date was on their files, probably provided by provincial vital statistics records, but no or little transition information is available. This group of patients may have moved from the region or province or decided not to be followed by the program. This would therefore result in a conservative estimate of transitions experienced.
It is true that there is variation among patients with respect to the time they have been cared for and followed by the PCP. To account for this variability or survival time (time between each patient’s date of enrollment and death), the log of survival was incorporated as an ‘offset’ variable in each regression model. This is reported in the Methods section, Analysis, Page 9, Paragraph 1, Line 2.

**Reviewer 3, Comment 4:** “Given the very skewed distribution of the number of transitions this is a difficult analysis. How have the authors accounted for this distribution?”

Response 4: Yes, we acknowledged the highly skewed nature of the number of transitions and, because this is ‘count’ data, we employed negative binomial regression to examine the association between total transitions and patient characteristics. This information may be found in the manuscript in the Methods section, Analysis, Page 9, Paragraph 1, Line 1.

**Reviewer 3, Comment 5:** “The authors have focused primarily on univariate rather than multivariate analysis. Many variables, e.g. age and diagnosis, are inter-related and a multivariate analysis would indicate the most important variables. It would also mitigate the problem of multiple statistical tests, which with a p level set at 0.05, would mean that 1 test in 20 would be significant by chance.”

Response 5: Actually we focused on the multivariate analysis and only included univariate or unadjusted figures in Table 2 for comparison sake. Text in the manuscript refers to the results of the final multivariate model and was noted as such (Results, Page 10, Paragraph 3, Line 2). In addition, to avoid confusion, all rate ratios (RR) reported as numbers in the test are preceded by the word ‘adjusted’. We agree multivariate tests would indicate the most important variables.

Reference to the univariate analysis was noted only in situations where the univariate results significantly differed from the results of the final multivariate analysis. These unadjusted estimates were not provided in the main text, only as part of Table 2.

**Reviewer 3, Comment 6:** “The results appear to be relevant to the literature on factors affecting place of death, and the authors should discuss this, relating their findings to that published in BMC Palliative Care and elsewhere.”

Response 6: Although this may be true, and in fact we did find an association between the number of transitions (specifically into hospital) and the location of death, this was not the thrust or direction of this paper. We have conducted and published analyses on the multiple hospitalization and place of death association but wanted to focus this work on the “movement” of patients prior to death. We would prefer, therefore, not to expand the discussion into that area for this paper.