Reviewer's report

Title: Experiences of patients, family and professional caregivers with Integrated Palliative Care in Europe: protocol for an international, multicenter, prospective, mixed method study

Version: 2 Date: 14 August 2014

Reviewer: Franca Warmenhoven

Major Compulsory Revisions

1. In methods, section ‘selection of IPC initiatives’, the authors propose to recruit different IPC initiatives in the study, three for Belgium and five for other countries. It is unclear whether only three initiatives will be recruited for Belgium compared to five for the other countries. In fact, it is also unclear why you choose for either three or five initiatives in any of the countries. Can you clarify why you have chosen or why you expect to be able to include 3-5 initiatives per country?

2. In methods, section patients and family caregivers, the authors aim to achieve a total sample of 138 patients and 138 family caregivers. Even with an attrition rate of 30%, this number of participants seems quite ambitious. I have doubts about the attainability of these numbers. This is related also to the section ‘data collection’, in which the authors report that they expect the entire duration of the study period to be eighteen months, including recruitment, which is a very ambitious planning. Furthermore, I would like clarification whether the authors aim to include six subunits per initiative or whether it will also be an option to include less or more subunits per initiative with a mean of six subunits per initiative.

3. In section methods, data collection, the authors say that bereaved carers may still be included in the study for the final follow-up. The authors have already referred to the existence of the post-bereavement version of the Canhelp Lite. It would be more clear if the authors would explicitly name the use of this version of the Canhelp Lite in bereaved caregivers. Furthermore, the procedure of data collection when a patient deceases is not clear. A bereaved family member may interpret questions in a different way. Please elaborate on how you will deal with the information gathered from bereaved caregivers. I am also interested in how you will use the patient diary information in the case of a deceased patient.

4. In the section methods, professional caregivers, focus group, it is unclear how many professionals will be included in the focus group and what kind of professionals will be included. Also it is not stated what the minimum of participants in the focus group will be, which professionals should be present for the focus group to take place, and what will happen if several professional caregivers in a subunit decline the invitation of the focus group. Indeed the authors broadly suggest the topics that will be discussed in the focus group, but a concept of the topic list or the method by which the topics for the topic list will be
defined should be given.

5. In the section methods, data management and analysis, the authors describe that researchers from each partner country will jointly develop a preliminary coding schedule with the results of the first two interviews. Will this procedure take place with both baseline and ending interviews?

6. In the section methods, data management and analysis, it is unclear how the focus group data will be managed.

Minor Essential Revisions

1. The reference of Lukas Radbruch indicates that he works in Leuven and the reference of Johan Menten indicates that he works in Bonn. This should be reversed.

2. In the methods section, participants (subunits), ICP should be IPC.

Discretionary Revisions

1. In the conclusion of the abstract the abbreviation IPC is used. Please add ‘(IPC)’ in the abstract ‘background’ where you use the term Integrated Palliative Care for the first time.

2. In the manuscript ‘Background’ the sentence that refers to the study of Epiphaniou (ref.17) is difficult to read. You may want to consider rephrasing this sentence.

3. Research questions: The main research question in this study is very broad in the sense that it includes experiences of patients, family and professional caregivers. However, it is not completely clear whether subsidiary question 2 also includes all of these 3 perspectives (family and professional caregivers). Furthermore, I wonder whether subsidiary question 3 and 4 will be related to the integrated palliative care pathways, which are the subject of this study.

4. The section methods, patients and family caregivers, semi-structured interview, describes how semi-structured interviews will be used to explore views of patients and caregivers. A few questions arise in this section: Who will perform the interviews? Will these interviews be performed with patient and family caregiver together at the same time? How will you deal with the influences that patient and family caregivers have on each other and how will you secure collecting data from both patient and family caregiver instead of collecting most data from the most dominant partner in the interview?

5. In the additional file 1: Caregiver network analysis questionnaire. This questionnaire may bring some unclarity (question 2) if ‘the how’ of the contact that the patient has with the caregiver is varying (eg. Sometimes telephone, sometimes face to face). It may be worthwhile adapting this question so more options are possible.

6. In the section methods, questionnaires, the authors indicate that the Palliative care Outcome Scale, is being translated into Hungarian. This information about Hungarian translation/availability misses in the case of the other questionnaires, Caregiver Reaction Assessment and Canhelp Lite. Either mention the state of
process in all questionnaires, or restrict this to the general remark that you have already made in the general questionnaires section.

7. Methods, ethical issues. I am surprised that the study does not have to go through a Dutch ethical review committee, but I trust that the same conditions apply to the Dutch participants compared to the participants from other nationalities.

**Level of interest:** An article of importance in its field

**Quality of written English:** Acceptable

**Statistical review:** No, the manuscript does not need to be seen by a statistician.

**Declaration of competing interests:**

I do not have any financial or non-financial competing interests relating to this manuscript. I have worked as a researcher at the University Medical Centre Radboud Nijmegen, department of Anesthesiology, Pain and Palliative Medicine until 2011 but have no current position there at the moment. My current work is at the K.U. Leuven, Academic Centre for General Practice.