Author’s response to reviews

Title: Volunteers in a biography project with palliative care patients – a feasibility study

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Author’s response to reviews:

Editor Comments:

1. There are currently two copies of your figures in the manuscript, please remove the copy embedded in the text.

Authors´ response: We deleted the figure in the text.

2. Please provide figure titles/legends under a separate heading of 'Figure Legends' after the References. If Figure titles/legends are within the main text of the manuscript, please move them.

Authors´ response: There were no other figures in the text.

3. Please add a section "Additional files" (after the References/Figure legends) where you list the following information for each additional-supplementary file in the file inventory:

- File name (e.g. Additional file 1)
- Title of data
- Description of data

We added a section as requested.
Authors´ response:

We would like to thank the reviewers for their comments and suggestions for improvement. We tried to consider all suggestions in the revision of the manuscript.

Preliminary note:

There are reviews and randomised controlled studies which demonstrated improvement of QoL and more specifically improving well-being and alleviating depression in the use of biographical interventions. Our small study cannot add any further information to that. The focus of our study is on volunteer biographers. The design of our study is complex so we decided to concentrate on the data concerning volunteers and deleted other results. Our study followed a strict protocol and we elaborated every step in the paper. We hope that these changes address the problems that the reviewers stated.

Reviewer reports:

Catherine Walshe, Ph.D., MSc., BNurs., RGN (Reviewer 1): Thank you for the revision of this manuscript. It is clearer now, thank you, but I think there are still some areas that require attention before this is suitable for publication I am afraid.

a) The feasibility question(s), aim(s) and/or objectives still need to be much more clearly articulated please both in the abstract and within the manuscript. It is still a struggle to me to understand exactly what elements of feasibility this study aimed to achieve. Whilst you have adopted the reviewers suggested objectives (I note we both identified similar issues with the original manuscript), I think these could be more clearly worded with reference to your original objectives, not those imputed (correctly or otherwise) by a reviewer. This confusion continues through the manuscript where it is very unclear which of your data collection methods maps on which feasibility question(s), and in the language used throughout which is not always one of feasibility. So I suspect you have questions like (and these need to be properly worded please)

i) Can we recruit and train volunteers to deliver this intervention (data collection - completion of training and volunteer interview? How do you know you can scale this up?)

ii) Is the intervention acceptable to patients (data collection - unsure - so perhaps this was not an objective?)

iii) Can the volunteers deliver the intervention safely and appropriately? (data collection - interview??)
iv) Can we collect data to understand the effect of the intervention in quality of life, and is this the correct outcome to measure? How many participants would we need in a full study? (data collection - completion of FACIT-pal??)

v) How long does the intervention take to deliver, and is this time appropriately spent?

etc. There may be others, some of these may not be your objectives, but I hope this helps to explain what I, as a reviewer, expected to see in this manuscript. This needs to be a thread running through the entire manuscript guiding the sample size required to meet these objectives, the data collection needed to answer your questions, and the analytical approach.

Authors’ response:

The following passages were added in the abstract and the background section to clarify the determinants of feasibility that we had tested in our study.

Abstract, page1, line 34f

For the purpose of this study, we evaluated resources such as time needed for training, coordination and supervision, outcome such as completion of the intervention in appropriate time and risks such as causing distress in patients or volunteers as major determinants of feasibility.

Background, Page4, line 98f

The overall aim of this study is to examine if a biographical intervention provided by skilled hospice volunteers is feasible regarding the following domains: i) do we have the resources for training, coordination and supervision; ii) can the volunteers finish the intervention comprising the interview and the writing in an appropriate time, and iii) are there indications for distress in patients or volunteers.

b) Unfortunately I still found the intervention to be underspecified. I quite understand and appreciate that there needs to be flexibility in the delivery of the intervention, but at the moment this seems under theorised and under specified such that it could not be replicated. I strongly suggest that the TIDIER guidelines are used as a clear guide to writing a short paragraph describing the intervention.

We followed your suggestion and structured the Methods section according to TiDieR. (page 5f partly without heading)
Brief name

We tested an “unstructured autobiographic storytelling” (Webster, Romanoff) delivered by volunteers.

Why

Studies have demonstrated that biographical interventions improve quality of life and decrease depression in palliative care patients. (Bohlmeijer, Pinquart, Guo, Keall 2015, Steinhauser 2008, Ando 2010, Chochinov, 2011, Hall 2011, Vuksanovic) Implementation in clinical practice is sparse. Volunteers have been able to deliver a reminiscence intervention. (Allen et al., 2014) However, the open question is if implementation of a volunteer-based intervention is feasible.

What

Materials

(1) Baseline evaluation with closed questions was used before the training in biographical work for volunteers. The structured questionnaire included seven questions about their skills, four questions on their appraisal of biography work, and six questions about their motivation. (see supplementary material)

(2) At the end of the project we performed a focus group interview. All volunteers were asked to talk about their experience along open-ended questions on the following issues: preparation, the interview itself, transcribing procedure, writing and their evaluation. (see supplementary material)

Procedures

Written consent and the self-administered questionnaire (1) were collected from each volunteer before starting the training.

Training

Volunteers were trained in biography work for 14 hours. This consisted of an introduction unit (2 hours) and three workshops à four hours. Learning goals included knowledge about influence of illness, goals of palliative care, importance of storytelling as a coping method, and options for biography work. Technical skills included active listening, mirroring answers and reflecting emotions, and skills to handle audiotapes and transcription software. Self-experience took a major time share so that volunteers were reflective to their own biography and learned how to handle challenging interview situations. Volunteers were taught to come to patients as a writer not as an investigator. Supervision was provided during the whole time and volunteers were accompanied in every phase of the project.
Intervention

All volunteers were informed when a patient had given informed consent to participate in the project. If volunteers could meet the patient in the following week they confirmed by mail. At the day of the interview they had a short briefing and received a dictaphone. One of the authors (MH) accompanied the volunteer to the patient, introduced them to each other, and left the room putting a `Do not disturb´ on the door. After the interview the volunteer came to MH and returned the dictaphone. The interview file was copied on an USB-stick and given to the volunteer. The volunteer received a short debriefing. The volunteer was asked to take notes of the experience and document the time needed. MH then visited to the patient to get his feedback on the intervention.

Evaluation

At the end of the project the participating volunteers were invited to a focus group interview. This session contained two rounds. In the first round each volunteer talked about his/her actions along the questions (2). In a second round all volunteers were invited to discuss and exchange their experiences. The focus group interview was audiotaped and transcribed verbatim.

Who provided

Skilled Hospice volunteers from a hospice volunteer service `Bonn Lighthouse´

How

Every volunteer interviewed a patient face to face and constructed a written narrative from the audiotaped interview which was then presented to the patient as a little booklet or a letter. The initial question asked was: “What do you want to tell? What shall I write down for you?”

Where

Patients were recruited on the Palliative ward of University Hospital Bonn.

When and How much

Data were collected between January and July 2018. Preparation and training took place from January till March 2018. Biography interventions were performed from April till June 2018. Interventions were planned in one or two sessions depending on the health status of the patient. However, all patients wanted to tell their story in one session. The focus group was held on the 25th of July 2018.

C) I am not sure that figure 1 is helpful, unfortunately, as this shows the timeline for the project, not the proposed timeline for data collection for a participant. As I reader I would wish to know
when baseline data were collected, when the intervention was delivered (and over what time period) and when follow up data were collected. If this all occurs within a week, I still have some concerns that FACIT-Pal may not be the best data collection tool, perhaps? Data on how long the study would take to set up however, is useful to researchers, and should be clearly detailed.

We deleted figure 1. Please see the additional information given in the methods section.

d) I have concerns that you should not be reporting an improvement in FACIT-Pal scores, given the small numbers involved. I would rather that you report any data on completion rates and completeness, any feedback on its use, and whether the data can be used to calculate the number of participants required in any full study.

See preliminary note. Data on the quality of life assessment were deleted from the manuscript in order to focus on the intervention performed by volunteers.

e) I think your conclusions on feasibility do not fully take account of the negative aspects of this study (e.g burden for volunteers, ability to recruit sufficient volunteers), whilst I can see that this intervention has potential. I would be more circumspect I suspect, and would prefer that recommendations for a full study are clearer.

The negative aspects you stress were mentioned by single volunteers but their appraisal of the project was positive. Difficulties were reported with the technical and organisational aspects such as computer compatibility problems (Mac or word), and estimation of time needed for transcription. We told volunteers that it will take 6 hours to transcribe an hour of interview. Some volunteers had not believed that. Volunteers reported positive about the interactions with the patients. Volunteers were so impressed by the openness and the courage of the patients that these positive experiences were worth the struggle. Of course we cannot exclude a risk of significant burden on patients or volunteers with the low numbers in this feasibility study but looking at the RCT of Allen et al. we find no description of burden in a larger number of volunteers (45 retired senior volunteers) or patients, and no problems with recruitment.
In summary, I remain interested in this as a volunteer provided intervention, and it clearly has potential. However I think that more attention to detail in the way that feasibility objectives are reported is required before this could be published.

Joe Low, Ph.D., M.Sc., B.Sc (Reviewer 2): I have read through the authors' responses to both reviewers' comments. I have also read through the authors' marked and revised manuscript and I am happy that most of the comments have been addressed by the new revised version.

My three outstanding comments are:

1) I accept that this study is under powered to detect any statistically significant difference and the authors state this categorically. However, when I asked about clinical significance, I wanted the authors to reflect if a 5 point improvement on the FACIT-Pall would be considered meaningful and real improvement to participants' quality of life. ie What does a 5 point improvement mean? This would be useful for the authors to discuss this briefly in the discussion.

See preliminary note. We deleted the information on quality of life in the manuscript in order to focus on the feasibility of the volunteer intervention.

2) The authors talk about how they would like to take this forward in their response to the reviewers, but don't say anything in their discussion about future direction in which we talked about 'planning to continue with the biographical intervention using trained volunteers. This will not be done as a clinical trial, but data from the ongoing quality management documentation can be evaluated descriptively with a larger sample size in the future'. Can the authors add this to the appropriate section in the discussion or highlight where they have written this (in case this reviewer missed it).

We inserted the paragraph as requested: Page 14, line 322

We are planning to continue with biographical interventions using trained volunteers from the volunteer service. This will not be done as a clinical trial, but data from the ongoing quality
management documentation can be evaluated descriptively with a larger sample size in the future.

3) In their Figure, what does the '18' represent? Weeks, days?

The “18” represents the year. Training was in February and March 2018, the intervention took place in April, May and June 2018. We deleted the figure because it did not seem to be clarifying.