Author’s response to reviews

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

Authors:

Michaela Hesse (michaela.hesse@ukbonn.de)
Simon Forstmeier (simon.forstmeier@uni-siegen.de)
Henning Cuhls (henning.cuhls@ukbonn.de)
Lukas Radbruch (lukas.radbruch@malteser.org)

Version: 1 Date: 01 Apr 2019

Author’s response to reviews:

We would like to thank the reviewers for their comments and suggestions for improvement. We did revise the manuscript accordingly.

Reviewer 1:

Catherine Walshe, Ph.D., MSc., BNurs., RGN (Reviewer 1): German volunteers in a biography project with palliative care patients – a feasibility study.

Title: I might recommend taking the country name out of the title, there is evidence that this can restrict readers. Otherwise this uses key terms.

We changed the title accordingly.

Abstract: This doesn't indicate what areas of feasibility this study sought to address. There isn't a sense of what design/method was used to address this question in the abstract. Qualitative content analysis is only mentioned as an analytical tool, rather than there being an overarching design. I am concerned that the abstract mentions 'benefit', given this is a feasibility study with only a few patients (the number of patients is not stated in the abstract, but implied as 9), I think this overstates these findings. Without feasibility objectives, it is hard to determine whether this study was feasible or not. I would suggest also being clear about the difference between a feasibility and a pilot study, as this is also called pilot in this abstract.
We added: Feasibility is encompassing resources, outcome and risks (line 34). Our findings are not representative due to the small number of volunteers and patients. ‘Patients expressed benefit’ (page 1, line 41) was changed into ‘patients provided positive feedback’.

This study aims to get a data basis to decide if involvement of volunteers in biographical work is possible with limited resources. Feasibility is encompassing resources such as time needed for training, coordination and supervision, outcome looking at patients’ well-being and volunteers’ distress and risks.

We deleted pilot (page 1, line 46).

Introduction. The background focuses on biographical therapeutic approaches, which is relevant to understanding this study, and draws from appropriate literature. It would, however, be helpful to indicate which of these interventions is the basis for the intervention tested in this study.

Our intervention was an open offer to patients who could choose whatever topic they want to talk about. Lindquist et al. (Reflections on using biographical approaches in end-of-life care: Dignity Therapy as example, Qualitative Health Research 2015, 25(I):40-50) raised awareness for reflection of complexities of everyday life and that “culturally sanctioned view of a perfect life with a happy ending for all” cannot be assumed. Therefore we did not want to use questions from Dignity Therapy or Life Review, especially as the interviews were conducted by volunteers. We took the intervention as provided by Hospice Wairarapa in New Zealand as an example (http://www.hospicewairarapa.co.nz/biography.html)

We were interested in story-telling as described by Romanoff & Thompson who state the therapeutic function of narrative.

We added the following sentence:

The intervention used was a short open biographical approach to foster story-telling. Patients could choose the topics they want to talk about. This intervention is in the style of Romanoff and Thompson who claim that narrations about life or illness have potential to seek for meaning (page 4, line 91f)

The rationale for volunteers delivering these interventions is, however, weaker, and this section could be enhanced with stronger argumentation. The rationale appears to be one of replacement of paid staff, which is often considered to be problematic in volunteering literature. I would suggest also drawing more clearly from the literature on volunteers and their roles and impact on people towards the end of their lives, the impact on them, and the feasibility of such interventions e.g. (Allen et al., 2014, Candy et al., 2015, Dodd et al., 2018, Hallett et al., 2012,
Morris et al., 2013, Mountain et al., 2015, Pesut et al., 2014, Walshe et al., 2016), but this is not an exhaustive list.

Interventions provided by professional staff are mainly crisis intervention, supportive therapy, and interventions for relaxation. (Mehnert Psychotherapie in der Palliativen Versorgung. PsychotherPsychMed. 2015;65(09/10):387-97.)

This restriction is due to resources of time and money. There are no biographical interventions provided by the health care professionals, so volunteers are not replacing them. Our underlying idea was to find a sustainable concept for the provision of biographical interventions. Before we got started we looked at experiences from other countries, such as Vivienne Pender, Giving voice to life: training volunteer biographers at Mary Potter Hospice, European Journal of Palliative Care, 2014,21(4); Lichter, Mooney, Boyd; Biography as therapy, Palliative Medicine 1993, 7:133-137; Beasley et al., The lived experience of volunteering in a palliative care biography service, Palliative and Supportive Care 2015, 13:1417-25. Our study looked at additional training in biographical interventions as we aimed for a diversification of the roles for volunteers. (Hesse, Radbruch, Pelttari, Scott, The full range of volunteering, 2014, PalliaMed Verlag, Bonn)

The following paragraph was inserted: (page3, line 57ff)

Narratives are an important tool to construct meaning, and there is a growing body of literature and research in the use of narratives in palliative care. (Romanoff, Breitbart, Park) Telling stories is an intrinsic part of human beings. An alleviating effect may be achieved by a nonjudgmental and interested listener. (Romanoff, Thompson) Volunteers` engagement with patients is a key resource (Walshe et al.) and is characterized by informality (Burbeck et al.) for they stand for unintentional awareness. Volunteers in palliative care prove responsibility of society and are crucial to guarantee future growth of hospice and palliative care as stated in the review of Candy et al. Involvement in biographical interventions meets the categories `being with´ and `doing for´ facilitating well-being as described by Dodd et al. The roles of volunteers can be described as ambiguous and this should not imply quasi-professional roles or substitutive roles. (Burbeck) Ambiguity should be a plus and stand for flexibility and patient-orientation.

AND (page 4, line 80f):

A randomized controlled study from Allen et al. (27) demonstrated that senior volunteers were able to deliver a reminiscence and creative activity intervention in an outpatient setting. Looking at the experiences of the volunteers with a qualitative approach (28) revealed a positive impact and personal benefit for the volunteers. The authors see a need for further research in the realm of implementation and in the long-term impact on volunteers.
The rationale for this being a feasibility study needs to be much more clearly articulated please. What were the elements of the study where feasibility needed to be determined? It is unclear if this is associated with training, delivering the intervention, or elements of the study such as sampling, data collection etc. This section (or more likely the start of the methods section) would be enhanced by stating a clear research question and feasibility objectives.

We added the following sentence as suggested by reviewer 2 (page 4, line 97-99):

This study has the following aims: i) the feasibility of training and engaging volunteers as a psychosocial intervention, ii) explore potential issues around organisation, resources and challenges; iii) evaluate potential effectiveness in improving patient outcome.

You also mention employing volunteers (p.3, line 72), but I don't think you mean employment as this implies payment?

We changed employing into engaging. Of course we did not mean payment.

It is also unclear why you suggest the intervention, in the hands of volunteers, is a psychosocial intervention rather than a psychotherapeutic intervention, and this needs a clear rationale and supporting evidence please.

Stating Romanoff and Thompson (“Meaning construction in Palliative Care: The Use of Narrative, Ritual, and the Expressive Art” in American Journal of Hospice and Palliative Medicine, Vol 23, No 4, 2006, 309-316.) who conclude in their study: ”The telling of the story to a willing, nonjudgmental companion acknowledges existing meanings and enables the construction of new meanings that may alleviate suffering.” Candy et al. concluded that “volunteers may be a key part of the resources needed to enable future growth” As Walshe et al. stated in “How effective are volunteers at supporting people in their last year of life? A pragmatic randomized wait-list trial in palliative care. BMC Medicine 2016) involving volunteers is appreciated by patients and families “but there is little evidence of their effect on care outcomes” Therefore we conducted a feasibility study looking at outcome and risks for implementing a volunteer provided intervention. Sustainability cannot be guaranteed by professionals due to limited resources.

Please see the paragraph already mentioned above

Methods. Unfortunately I found this section challenging to follow. Could I suggest that this is re-ordered following reporting guideline such as COREQ or SRQR, and using the TiDiER guidelines to report the details of the intervention. Subheadings guiding the reader to sections on
setting, population, sampling, intervention, data collection, data analysis etc. would be very helpful. What is the overarching design/method of the study?

We restructured the methods section and added subheadings.

The study was designed as an open uncontrolled mixed methods study, evaluating qualitative and quantitative data in a small convenience sample. (page 5, line 108)

Sampling: How were volunteers sampled from the pool of available volunteers? Were any new volunteers recruited to deliver this service? Did they have to have volunteered in the specific hospice setting previously, or could their 'training in hospice care' have been received elsewhere? On what basis was the 'selection' made? May there have been some form of bias? What were the inclusion and exclusion criteria? This is an important feasibility question, as if they were selected informally against particularly rare characteristics (for example their educational background, or a 'sense' that they could provide this intervention), then this may mean that it is not possible to scale up this intervention. What was the sample size required to determine feasibility?

We added the following sentence:

The ward has a cooperation with hospice service Bonn Lighthouse. (page 5, line 110)

Participants Volunteers were recruited by the coordinator on a supervision group meeting. There were no exclusion criteria. Inclusion criterion was training as a hospice volunteer was completed (120 hours plus supervision of first cases). (page 5, line 112ff)

Sample size was not calculated as we planned for each trained volunteer to interview one patient. The manuscript was revised:

We did not calculate sample size for feasibility but rather requested that every volunteer interviewed a patient face to face. (page 6, line 122)

Lighthouse has only volunteers who were trained in their own courses.

How were patients identified and sampled, and against what inclusion and exclusion criteria?

We added the following sentence:

Inclusion criteria were >18 years, German speaking, no psychiatric diagnosis, no mental constraints. (page 5, line 115)

Volunteers and patients were sampled by convenience. (page 6, line 143)
Intervention: As above, I would suggest presenting this explicitly using the TiDIER guidelines. I assume this includes both the training, and the delivery of the biographical work? Is the written booklet part of the intervention? How was the training determined? Is this a 'standard' training for this biographical intervention? Indeed, is this a specific biographical intervention, as per the earlier introduction section? What is the existing evidence that underpins the effectiveness of this intervention per-se, delivered by paid staff rather than volunteers? Was the intervention modified in any way to be delivered by volunteers?

The methods section was restructured. (page 5, line 102ff)

Data collection.

What was the purpose of the questionnaire to volunteers at the start? Was this a validated questionnaire? Can the questionnaire be appended please.

The questionnaire was developed for this study. Aim of the questionnaire was to find out about the motivation, and appraisal and for reasons of evaluation (triangulation with content analysis).

We add the questionnaire to the supplementary material.

Why was quality of life assessed?

Was this presumed to be the outcome of any larger study, and why was FACIT-Pal 14 chosen as an outcome measure? Is this a common outcome tool used in such biographical interventions? Are the elements within it felt to be those that may be impacted by the biographical intervention?

Literature shows effects of biographical approaches on depression and QoL. Regarding the vulnerability of our patients we decided to look for a validated short tool. Together with the EORTC-QLQ-C15-PAL the FACIT-Pal is one of the most common outcome measures. In line with other research done in our department we selected the FACIT-Pal with 14 items.

When you say assessed pre and post intervention, with what timing, especially how long after the intervention was this measured? The FACIT-pal14 instrument used asks for an appraisal over the last 7 days, so there has to be a gap between administrations otherwise there is no purpose to the assessment, the number of days/weeks between assessments needs to be given.

The tool was assessed together with the informed consent and then one week later after the interview with the volunteer. The following sentence was inserted:

Time span between pre and post intervention was planned with 7 days. (page 6, line 142)
At what stage after completing the biographical intervention were volunteers interviewed - it is unclear if this was at the end of overall project, or just after the end of their own involvement. What is meant by 'guided interview'? Can a complete topic guide be given please.

Please see the flow-chart. Training phase of the volunteers was in February and March 2018, recruitment and interview in April, May and June. Volunteers were asked to make notes after the interview about their impressions, emotions and thoughts. The overall evaluation took place in July. We add the interview guideline to the supplementary material.

What form of content analysis was used?

Data were analysed using the descriptive and qualitative content analysis. (Elliott, Timulak) The main themes of the evaluation were inductively applied, and data were sorted into categories. Quality criteria of qualitative research are replicability, triangulation and reliability. (Mayring 2000, Flick) The data was coded independently by two researchers for reasons of intercoder reliability. (Flick) For reasons of replicability interpretation of data was structured thoroughly and categories were defined and discussed till consensus was reached. For triangulation, categories from the analysis were compared with the items of the questionnaire. (page 7, line 160ff)

What were the dates of data collection? Whilst research ethics committee approval is noted, I can't see any details of other ethical procedures such distress management procedures etc.

The following sentences were inserted:

Data collection comprised a questionnaire and an audiotaped evaluation interview of the volunteers. Data collection of patients comprised FACIT-Pal pre and post intervention, the audiotaped interview and the booklet made by the volunteer. Analysis in case of the patients is restricted to FACIT-Pal. (page 5, line 117f)

The palliative care team includes a psychologist and volunteers as well as patients were made aware of this resource in case of distress related to the intervention. (page 6, line 121)

Results. Can I suggest presenting the demographic and other descriptive data about both volunteer and patient participants in a single table, so it is easier to see these details on gender, age, marital status, length of interview, transcription etc. Without details of the feasibility objectives of the study, it is hard to interpret whether the data collected indicates feasibility or
not. Clearly, they were able to deliver the intervention with a limited range of participants, but I cannot assess if this indicates feasibility or not. This was, however, not without burden, with adverse data on the burden of this intervention on volunteers (e.g. time for transcribing etc.).

We organized the demographic material into tables. In addition we made a flow-chart of the project. Please find the diagram at the end of this letter, page 14.

We added the following paragraph into the discussion section:

Larger samples may be required to evaluate the impact of the additional burden with time needed for transcription of the interviews and supervision on volunteers motivation, as well as for evaluation of effectiveness and risks. However, our small sample study demonstrated that the biographical intervention can be provided by volunteers, recommending more research in this area. (page 14, line 333)

FACIT-pal scores are given, but more information is required here on not only mean scores, but also range etc. given the small sample. Whilst there is a mean increase reported, this is not interpreted with reference to norms for FACITpal, nor data that indicates MCID or similar e.g. (Kavalieratos et al., 2016). How do these data compare to outcome data from the chosen biographical intervention?

Whilst it is stated that an effect size could be calculated from these data, it is not clear why this is not done.

FACIT-Pal is an acknowledged QoL assessment (Lyons 2009). Norms for FACIT-Pal are “After reversing proper items, all subscale items are summed to a total, which is the subscale score. For all FACIT scales and symptom indices, the higher the score the better the QOL.” (FACIT Administration and Scoring Guidelines).

As we had designed the feasibility study with a small convenience sample with one interview per trained volunteer, we decided not to calculate statistical data for this small convenience sample, but rather present descriptive and epidemiological information.

We added the range of scores.

Mean FACIT-Pal scores increased from 36.87 (range 19-50) before the intervention to 41.37 (range 24-55) after the intervention. (page 8, line 184)
Unfortunately I cannot see how the volunteer questionnaire adds to knowledge, but again these data would be better presented in a table or other similar format.

Please find the questionnaire attached to this document.

Discussion. As a feasibility study, it would be usual for the discussion to focus on the feasibility objectives, with recommendations for a full study. This is not how this discussion is presented. Occasionally it strays into re-presentation of findings, which should be avoided. I think the discussion needs to be reconsidered, with a different approach taken in terms of the literature to which these findings are presented.

We organized the discussion along the feasibility objectives discussing the literature.

Please check throughout for grammar and syntax, as there are some errors in English expression.

References


Reviewer 2:

Joe Low, Ph.D., M.Sc., B.Sc (Reviewer 2): This paper describes a small feasibility study looking at training volunteers to deliver a biographical intervention in a specialist palliative care unit. As there are few papers which specifically look at volunteers delivering an intervention, this paper is both novel and unique, and is worth considering publishing.

However, before it is considered suitable for publishing, it needs to be both restructured (to make it easier for the reader to follow the logic of the paper) and rewritten to provide more details, before I can recommend it to be accepted for publication.

I will address these section by section.
1. Keywords: I would remove the qualitative as you use a mixture of qualitative and quantitative data

We changed the text accordingly.

2. Introduction:

Main comment: More details are needed about what biographical interventions are, in particularly what changes are they trying to achieve in a person to improve quality of life?

The following paragraph was inserted: (page3, line 57ff)

Narratives are an important tool to construct meaning, and there is a growing body of literature and research in the use of narratives in palliative care. (Romanoff, Breitbart, Park) Telling stories is an intrinsic part of human beings. An alleviating effect may be achieved by a nonjudgmental and interested listener. (Romanoff, Thompson) Volunteers` engagement with patients is a key resource (Walshe et al.) and is characterized by informality (Burbeck et al.) for they stand for unintentional awareness. Volunteers in palliative care prove responsibility of society and are crucial to guarantee future growth of hospice and palliative care as stated in the review of Candy et al. Involvement in biographical interventions meets the categories `being with´ and `doing for´ facilitating well-being as described by Dodd et al. The roles of volunteers can be described as ambiguous and this should not imply quasi-professional roles or substitutive roles. (Burbeck) Ambiguity should be a plus and stand for flexibility and patient-orientation.

Your sentence in the discussion, (p8, l191-200) would be more appropriate in the introduction section.

The comparison with Chochinov´s provision of Dignity Therapy is part of the discussion whether volunteers can provide this intervention. We organized this part along feasibility objectives and think that citing Chochinov here is important for representing the current status of research.
Other comments:

a) On p3, l60-61, were these biographical interventions delivered by trained personnel? Please clarify.

Both references are reviews. Fitchett et al. included 12 studies to Dignity Therapy where Dignity therapists were providing the intervention. They raise the question whether the therapist should be a generalist (nurse or physician) or a specialist (psychologist, chaplain) and who should administer the intervention in a real-life care setting. They describe the intervention as costly and time-consuming.

The review of Keall et al. looked at Life Review in 14 studies delivered by social worker, nurses or clinical psychologist. They assume that interventions are not widely implemented though they are helpful, because they are perceived to be time-consuming. They see potential that interventions could be conducted by personal care attendants or trained volunteers. “This flexibility may improve uptake of life review interventions as psychosocial professionals may not always be available and patients may be reluctant to engage with them because of the stigma of mental ill-health.”

We added the following sentence to clarify:

Fitchett et al. describe Dignity Therapy as costly and time-consuming and discuss the question who should provide the intervention. Keall et al. elicit the limited implementation from perception of time and resources. They see potential in administering interventions by trained volunteers. (page 3, line 73-76)

b) Under the aims of the study, I would list out the aims of the study as follows: 'This study has the following aims: i) the feasibility of training and employing volunteers as a psychosocial intervention, ii) explore potential issues around organisation, resources and challenges; iii) evaluate potential effectiveness in improving patient outcome.

We changed the text accordingly.

This study has the following aims: i) the feasibility of training and engaging volunteers as a psychosocial intervention, ii) explore potential issues around organisation, resources and challenges; iii) evaluate potential effectiveness in improving patient outcome. (page 4, line 97-99)
c) Minor point: P3, l64 - insert 'and the' in between words 'New Zealand' and 'United Kingdom'.
We changed the text accordingly.

3. Methodology
Main comment: This section would benefit from being restructured and sub-divided, which would make this section clearer and more transparent for readers. I would recommend the subsections used for structuring randomised control trials (though I recognise that this is not an RCT):
Design, setting (of study), Participants, Inclusion criteria, exclusion criteria, recruitment, intervention (description), procedure/data collection, data analysis.
We restructured the methods section and added subheadings.

Within these subsections, the authors can clarify the following points:

a) How did the main author decide which volunteers were assigned to which patients?
It was a convenience match.

b) Recruitment:
i. Which hospice volunteers are being recruited? Was every volunteer eligible to be trained?
The ward has a cooperation with Hospice Bonn Lighthouse. Every volunteer who had finished the training was eligible.

Participants Volunteers were recruited by the coordinator on a supervision group meeting. There were no exclusion criteria. Inclusion criterion was training as a hospice volunteer was completed (120 hours plus supervision of first cases).(page 5, line 112)

ii. Patients recruited - was there an eligibility criteria? In-patient or out-patient?
All patients were receiving palliative care on the ward of University Hospital Bonn.

Patients were recruited on the Palliative ward of University Hospital Bonn by one of the authors (MH). Inclusion criteria were >18 years, German speaking, no psychiatric diagnosis, no mental constraints. (page 5, line 115)
c) Intervention:

i. Was it one session or more?

Intervention was planned in one or two sessions depending on the health status of the patient. (page 7, line 145)

ii. Who delivered the training session? Who provided the supervision to the volunteers and how often? How qualified were the trainers to deliver the biographical intervention?

Training and supervision were delivered by a very experienced social worker and a psychologist. Supervision was available during the whole project on demand and planned after each interview.

iii. Was there a criteria matching volunteers to patients?

No.

iv. Timeframe of study: what month and year did recruitment for the study begin and end?

The study ran from February to July 2018. Please look at the diagram at the end of this letter, page 14

d) To attach the questionnaire given to volunteers (p4, l90) in an Appendix. Was this a structured standardised questionnaire or a self-constructed questionnaire with open questions?

The questionnaire was constructed for this study. Aim of the questionnaire was to find out about motivation and appraisal of biography work and for reasons of evaluation (triangulation with content analysis).

We add the questionnaire to the supplementary material.

e) Not clear from the current methodology section what data was collected to answer the specific aims of the feasibility study? This needs to be made more clearer and put in the 'Procedure' subsection, especially if answering the questions on organisation, resources and challenges. I am unclear how this data was collected? Were volunteers later interviewed about these questions?
Data collection comprised a questionnaire and an audiotaped evaluation interview of the volunteers. Data collection of patients comprised FACIT-Pal pre and post intervention, the audiotaped interview and the booklet made by the volunteer. Analysis in case of the patients is restricted to FACIT-Pal. (page 5, line 117 f)

Please see the methods section.

In addition we made a flow-chart for organisation of the project

4. Results

Main comments:

a) I suggest that the authors should subdivide their findings to answer the questions highlighted in the aims of their study. I found it difficult the main themes coming out from the analysis and how this related to the aims of the study.

We restructured the paragraph along the subthemes of feasibility tested, please look at page 7, line 167ff

b) The qualitative analysis is currently very descriptive. However, one of the key strengths of qualitative research is to allow a deeper understanding of the experiences/phenomena being explored. In some cases, it would be interesting to explore some of the initial points raised to give a deeper understanding of the concept described. For example, on p6, l.138, the authors comment that 'the interview was described as a no-brainer' - what are the authors trying to convey in this context? It may be that the authors are limited with doing this analysis with the data they have and that is fine but this needs to be acknowledged in the discussion.

Volunteers were surprised that patients told their stories without interruption or encouragement to go ahead. This was described as “Selbstläufer” and translated as no-brainer. The German expression means s.th. going by itself. Limitation of the study is due to translation.

c) I recommend that the authors review the number of quotes they use. I accept that quotes represent important evidence to support the themes identified in the study. However, many of the quotes used in this paper are very descriptive and short, and the point from them could be written as part of the text outlining the different aspects identified the theme identified.

Research on volunteering is often characterized by writing about volunteers without giving voice to them. We found it an important addition to add the volunteer perspective in the evaluation.
d) Minor points:

i) What is meant by 'non-homogenous' in this context? (p6, 142)?

Burden of transcription and writing was judged very differently. Some volunteers reported no difficulties and had even fun, others struggled with technical devices or complained about the time needed.

ii) Replace 'will' with 'would'. P6, l131.

We changed the text accordingly.

5. Discussion:

a) Whilst the key findings highlighted are clear, the result section needs to be restructured to make it clear where these findings initially come from (see suggestions in results section).

The authors may want to discuss whether an increase of 5 points on the FACIT-Pal score is clinically significant.

As we had designed the feasibility study with a small convenience sample with one interview per trained volunteer, we decided not to calculate statistical data for this small convenience sample, but rather present descriptive and epidemiological information.

Also replace the word 'demonstrated' (p8, 1183) with 'suggest'.

We changed the text accordingly.

b) The paragraph starting with Chochinov et al (p8, 1191 - p9, 1200) - may be more appropriate in Introduction section (see Introduction - main comment).

See your point 2. The comparison with Chochinov’s provision of Dignity Therapy is part of the discussion whether volunteers can provide this intervention. We organized this part along feasibility objectives and think that citing Chochinov here is important for representing the current status of research.
c) Likewise, review whether the following paragraph starting with 'Volunteering - p9, 201 to l213, should be in the introduction.

We transferred this section from line 201 to line 206 into the introduction. Line 207 to line 213 was transferred to the results section because we compare the self-rating with the transcript of evaluation. (green)

d) I would like the authors to discuss their ideas about how they would use their findings from this study to improve the delivery of this interventions and how one would evaluate this intervention in the future.

We are 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.

Flow chart of the project