Author’s response to reviews

Title: An exploration of the conceptual understanding of Pediatric Palliative Care: A health care providers' perspective in Switzerland.

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Author’s response to reviews:

The authors sincerely thank the editorial board member for their thoughtful comments and suggestions. We have addressed all of the remaining concerns.

REQUESTED REVISION 1:

A better rationale and specific detail about the lack of informed written consent needs to be provided. This issue was raised by Reviewer 1 and the authors’ response of “Since all the focus group discussions took place with professional healthcare experts, who only had a limited time for study participation and because our study had no risk to their health and well-being, we preferred oral over written informed consent” is insufficient. Preferring oral consent over written consent and substantiating this decision due to a lack of time is illogical and feels like the authors are skirting the issue. Further, please confirm whether this was the ruling of the REB or simply the authors’ personal opinions as it seems odd that an REB would approve a protocol with no written informed consent. Likewise, talking about death and dying is not a benign issue—to suggest that there is no risk to HCPs emotional wellbeing is an understatement. This raises an additional important issue—was REB approval granted for this specific sub-study, including waiving the need for a written consent form? While the authors indicate REB approval for the larger study was granted please confirm that the qualitative arm of the study, including a statement that REB waived the need for written consent, was granted.
Authors’ response:

We thank the editorial board member for the comment concerning our informed consent procedure. We apologize if our previous answer was not sufficiently clear and we fully understand the expressed concern. It was certainly not our intention to skirt the question.

The main reason for the oral consent procedure is that in Switzerland interviews with health care professionals (not patients) are outside of the human research act (our research did not relate to an identifiable individual) and do not require research ethics committee (REC) approval. In spite of approval not being required we submitted the project, including this specific sub-project - to the REC and it was approved.


We do agree with the editorial board member that palliative and end-of-life discussions within pediatrics are sensitive issues, and might have a risk for healthcare professional’s emotional well-being. However, from an ethical point of view, for minimal risk research involving interviews or questionnaire studies with “non-patients” such as health care personnel whose data (transcripts or questionnaires) are anonymized, oral consent and active participation are ethically considered sufficient and proportionate.

As stated previously, that does not mean that the informed consent procedure was not respected. To make sure that our experts were clearly informed, we did the following:

a) We sent a letter with information on the study, the voluntary nature of their participation to each focus group participant before the actual group discussion so that they could read over the study aim with calm;

b) We reiterated the content and the aim of the study before the start of the focus group and responded to the participants’ remaining questions before starting the focus group discussion;

c) We registered the oral informed consent of each participant upon consent;

d) Transcripts were returned to participants for revision and which time they could still withdraw the data that they had shared.

For changes in the text see Methods Section p. 7 (line 160-165): From an ethical point of view, for minimal risk research involving interviews studies with health care professionals whose data (transcripts or questionnaires) are anonymized, oral consent and active participation are ethically considered sufficient and proportionate. Furthermore, in Switzerland interviews with health care professionals (not patients) are outside of the human research act and do not require ethics committee approval.
REQUESTED REVISION 2:

Please provide the interview guiding questions as an appendix so that readers can see the linkage with your results.

Authors’ response:

We thank the editorial board member for this useful suggestion. We have included (appendix) that part of our interview guide that relates to the data presented in this paper (see p. 7-8, line 173-180).

REQUESTED REVISION 3:

Please provide greater detail on how participants were actually recruited. The authors indicate that a list of names was given by the local recruiter of individuals who wished to participate but what initial info was given by the recruiter (was this the info sheet? Or was the info sheet provided after recruitment?)? When was oral consent provided and how was this obtained (did the authors get in touch with the participants or was this done by the recruiter?)? Please provide greater detail.

Authors’ response:

We thank the editorial board member for asking us to elaborate on the recruitment procedure. The recruitment phase consisted of two phases. The initial recruitment was done by the SPOG reference person who identified the interested team members. This reference person informed all potential participants about the overall aim of the focus groups and their confidential nature (they received a written document with the description of the project). Upon consent of the participants, the recruiter then gave the research team a list of team members who had expressed interest to participate. Each of these persons received the participant information sheet from a member of the research team via email, immediately after recruitment and then again (as reminder) some days before the actual date of the focus group discussion to give participants enough time to read over the participant sheet. Oral informed consent was obtained before the start of the focus group by the moderator and registered upon consent of the participants.

For changes in the text, see Methods Section p. 6 (line 144-151):

The reference person informed all members about the overall aim of the focus groups and their confidential nature. Upon consent of the participants, the recruiter then gave the research team a list of team members who had expressed interest to participate. Each of these persons received the participant information sheet from a member of the research team via email, immediately after recruitment and then again (as a reminder) some days before the actual date of the focus group discussion to give participants enough time to read over the participant sheet. The research team sent a request to all participants to find a common time to carry out the focus group discussions.
See also p. 6 (line 159-160): Oral informed consent was sought from all participants prior to the start of the focus group and registered upon consent.

REQUESTED REVISION 4:

It seems that there are two proverbial ‘white elephants’ that would be beneficial to mention in the discussion section. The first is one of the greatest barriers to palliative care integration—HCPs themselves—a finding that has been mentioned in numerous adult studies. The addition of a question to address this in the interview guide would have generated this data (which should be mentioned as a limitation) but as importantly it seems ironic that participants identify parents as barriers but not themselves. Obviously, this is in part due to the sample being entirely HCPs but there seems to be a bias towards blaming parents when HCPs are often as, or more to blame for the lack of integration of PPC. While this was touched upon in the Operational Definition section (which I suggest be modified to ‘Operational Definitions and Operationalization of PC’ to better reflect the data) this represents some important shadow data that needs to be more thoroughly addressed. This leads to the second white elephant—societies view on death and dying. While addressing this in detail is beyond the scope of this paper, it seems that the barriers of PC is really a micro issue of a much larger macro issue, namely societies adverse relationship with death and dying. This would be worth mentioning.

Authors’ response:

We thank the editorial board member for the suggestion and have changed the title of the paragraph from: operational definitions to “Operational Definitions and Operationalization of PC” (see results section p. 10, line 250)

We fully agree with the editorial board member that healthcare professionals’ attitude is often an important barrier to the timely integration of palliative care in pediatrics. However, we believe that this was also evidenced by our research results and emphasized in our discussion section (we have provided examples below with page numbers). We have reinforced some of the previous paragraphs covering this issue (newly added text is put in bold here below).

Likewise, we do believe that also the societal view on death and dying was addressed in our paper (see examples noted below with page numbers). We defend the thesis that the problem is not so much with death or dying but with the way in which the topics of death and palliative care are often discussed, i.e. in terms of choice and autonomy, and that this might be incompatible with the life-world of children. Again, we have reinforced some of the paragraphs that cover this issue (newly added text is put in bold here below).

a) Examples regarding HCP’s attitude

Newly added emphasis has been put in bold in the answers to the reviewer
Results section, p. 12 (line 284-286): Some participants acknowledged that their own attitudes towards PPC might negatively influence those of families’ and further compromise timely implementation of PPC (see Table 3.2, section a).

Results section, p. 14 (line 336-338): Finally some care providers highlighted the importance of having an external specialized PPC team as this could offer an additional perspective on the situation and provide support to the primary team, who might be too emotionally involved to start PPC in a timely manner.

Discussion section, p. 15 (line 362-368): they also emphasized that the transition from curative to PPC is not abrupt, but is actually a rather gradual process during which both families and healthcare providers slowly but steadily become aware of the need to re-direct the care provision. Understanding PPC as non-curative was considered necessary to generate this change in attitude. Some participants expressed the concern that “mixing” the two care approaches might cause confusion among both family and staff members and thus be counter-productive.

Discussion section, p. 15 (line 372-375): participants believed that nurses are more pro-active than physicians in encouraging PPC. Various interviewees recognized their own personal difficulties with the transition of treatment goals and welcomed the intervention of a specialized PPC team to lessen the burden.

Discussion section, p. 16 (line 387-390): Prior studies suggest that negative attitudes towards PPC among patients and families are often influenced by staff members’ own negative image of PPC. Some of our participants seemed to confirm these findings.

b) Examples regarding death and dying (society):

Discussion section, p. 16 (389-398): Some of our participants seemed to confirm these findings and this might confirm the idea that like many Western societies, Swiss society is still death-denying. Still we believe that given the centrality of death and dying in the Swiss public debate, it is difficult to maintain that this topic is still taboo. Hence, it is crucial to better understand care providers’ own perception of PPC to comprehend their aversion of the term palliative care. Our results show that various participants personally disliked the term “palliative care” not, or at least not primarily, because of its strong association with death or dying (many of them, in fact, were in favour of understanding PC as non-curative!) but because they considered it to be a concept that is incompatible with children’s everyday life.

Discussion section, p. 17 (line 410-417): Although we cannot address this topic extensively here, we should keep in mind that both on an institutional level and in the public debate, PC is often discussed and promoted as a life- and choice-affirming alternative to euthanasia and physician assisted suicide as PC intends neither to hasten nor postpone death and patient preferences are heavily promoted in the WHO definition of PC6, 52. This means that PC is often debated within a context of autonomy and choice in which planning towards and acceptance of death are actively encouraged. This may explain why some participants considered the concept of PC to be out of touch with children’s perspective.
Conclusion, p. 19 (line 474-482): Further, although PPC has increasingly profiled itself as being concerned with the patient’s quality of life (rather than with death) this shift has not overcome all stigmas. Therefore, perhaps the conceptual obstacle to PPC is not so much death itself, but the way in which PC is discussed on both a policy level and in public debates, that is, in terms of choice, autonomy and personal development. This interpretation could find support in the fact that our participants considered the term “palliative care” to be out of touch with the child’s perspective and preferred to use synonyms that are closer to PC’s original aims: to offer support to patients and families in pain, anger, sadness and laughter without any normative expectations.