Author's response to reviews

Title:'From activating towards caring '. Shifts in care approaches at the end of life of people with intellectual disabilities; a qualitative study of the perspectives of relatives, care-staff and physicians.

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Thank you for the comments on our manuscript. We give a detailed point-by-point response to the reviewers’ comments below, indicating how and where the manuscript has been revised.

Thank you for giving us the opportunity to improve the manuscript.

**Reviewer # 1 (Irene Tuffrey-Wijne)**

**MAJOR COMPULSORY REVISIONS**

Reviewer # 1: “I found the terms "semi-structured interviews" and "qualitative" somewhat inadequate in describing the study design. I would urge the authors to be more specific (eg "Retrospective case study design"). “

  We agree with the reviewer that the description of the design can be more specific. On page 5 we added that the study used a ‘retrospective case study design’.

Reviewer # 1: “I would also like to see more detail on the data collection tools (interview schedule) and its development. What were the interview questions/topics based on? Was there a theoretical research framework? (It might help to see a table or figure with the interview guide).”

  We added the following information about the development of the topic guide on page 6. We also included a table with the main interview topics.

  *The topic guide was developed in two stages: 1) the first draft of the topic guide was inspired by elements in the WHO definition of palliative care [www.who.int/cancer/palliative/definition/en] and literature regarding end-of-life care for people with intellectual disabilities[e.g. Tuffrey-Wijne et al., 2003, Tuffrey-Wijne et al, 2008, Wagemans et al., 2010 J. 2) This draft guide was discussed within a group of six experts working in the field of end-of-life care for people with intellectual disabilities, after which the guide was refined and finalized. The first question in the topic guide was what had made the strongest impression on the interviewee during the period of end-of-life care. Subsequent topics or questions concerned the care provided, communication with the person with ID, communication among professionals and between professionals and family, end-of-life decisions and dealing with loss. Table 2 presents an overview of the main topics. The order in which topics were discussed varied, depending on the course of the interview.*
Table 2.

<table>
<thead>
<tr>
<th>Opening question</th>
<th>What made the strongest impression on the interviewee during the period of end-of-life care?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Topic 1</td>
<td>Marking the start of palliative phase, communication about the diagnosis</td>
</tr>
<tr>
<td>Topic 2</td>
<td>Primary care process (e.g. pain, other physical symptoms, physical care, psychosocial well-being and spiritual well-being)</td>
</tr>
<tr>
<td>Topic 3</td>
<td>Decisions at the end of life</td>
</tr>
<tr>
<td>Topic 4</td>
<td>Communication with the person with ID</td>
</tr>
<tr>
<td>Topic 5</td>
<td>Autonomy of the person with ID</td>
</tr>
<tr>
<td>Topic 6</td>
<td>Transitions (e.g. changes in place of care or caregivers)</td>
</tr>
<tr>
<td>Topic 7</td>
<td>Communication and cooperation with relatives</td>
</tr>
<tr>
<td>Topic 8</td>
<td>Care for relatives (e.g. dealing with loss)</td>
</tr>
<tr>
<td>Topic 9</td>
<td>Fellow residents</td>
</tr>
<tr>
<td>Topic 10</td>
<td>The funeral</td>
</tr>
<tr>
<td>Topic 11</td>
<td>Aftercare</td>
</tr>
<tr>
<td>Topic 12</td>
<td>Care for carers (e.g. dealing with loss)</td>
</tr>
</tbody>
</table>

Reviewer #1: “I gather the selection of participants was purposive rather than random or convenience? Please state. Did the sampling strategy lead to any limitations in the study? (perhaps not... I do note that saturation was reached), if so, please include under “strengths and weaknesses”). Overall, studying twelve cases with 35 1-2 hour interviews is an adequate amount for a sound qualitative study, so the findings do seem to rest on a good amount of data.”

The selection of participants was indeed purposive. The sampling strategy was aimed at including a relatively diverse set of cases regarding age, living situation (own apartment, group home, residential home), place of death (own home, parents’ home, intensive care facility provided by an ID care service, hospital, hospice), kind of disease and severity of ID (mild, moderate, severe ID). The sampling strategy led to a rich set of interviews, enabling us to study shifts taking place within the end-of-life care of various people with ID, seen from various perspectives. The sampling strategy did not lead to any limitations in the study. We have described the selection of participants more extensively on page 7:

*Participants were selected purposively in order to obtain a relatively diverse set of client cases with regard to age, living situation (own apartment, group home or residential home), place of death (own home, parents’ home, intensive care facility provided by an ID care service, hospital or hospice), kind of disease and severity of ID (mild, moderate or severe ID).*
In this way, a variety of situations could be taken into account in the study. The number of cases was not predetermined. Rather, data collection and analysis were conducted in a cyclical process in accordance with key principles of qualitative research [Green and Thorogood, 2004]. Data saturation [Ando et al., 2014] was attained after twelve cases.

Reviewer # 1: “With regards to the research question (last paragraph of background section), the author states that "THIS PAPER will address the following research questions..." Does this mean that this was part of a study with wider aims than the ones addressed in this paper? If so, please state. If not, it would help to have the aim of the study clearly set out here.”

We understand the reviewer’s confusion. This paper was indeed part of a study with a wider aim. To make the wider aims and scope of the study clearer to readers, we added the following information to the Methods section (design) on page 5:

This paper is part of a wider study set up to increase knowledge about end-of-life care for people with ID in the Netherlands. From the inductive analyses of the data it appeared that some major shifts in care approaches were taking place. These shifts are described in this paper. Another paper, based on the same qualitative data, describes another main theme emerging from the analyses, namely how care providers try to respect the autonomy of people with ID at the end of life (Bekkema et al., 2014).

MINOR ESSENTIAL REVISIONS

Reviewer # 1: “1) Definitions and terminology: In a palliative care journal, it is essential to include a definition of "intellectual disabilities", as this term is not universally understood.”

We agree with the reviewer and added the following definition to the introduction (page 4).

Individuals with ID are characterized by significant limitations, from before the age of 18, in both intellectual functioning and adaptive behaviour [Schalock et al., 2010].

Reviewer # 1: “"End-of-life care" has different meanings in different countries: some (incl UK) use it interchangeably with "palliative care", whereas many others see it purely as the care in the last few days of life. I suggest changing this term to "palliative care" and clarify that it can start well before the final decline (as, reading the paper, I gather the authors are not just talking about the final days).”

In our study, end-of-life care refers to an extended period, which may start early in the trajectory of a life-threatening illness. We see the importance of making our definition clearer to readers, so we extended our definition on page 4 as follows:

End-of-life care may start early on in the trajectory of a life-threatening illness and can be typified as multidisciplinary care aimed at enhancing the quality of life by assessing and
relieving pain and other distressing symptoms, while taking account of the physical, psychological and spiritual needs of patients and their families.

Reviewer # 1: “Social worker” (this term is used several times, for example in Eleanor’s case study): I gather that in the Netherlands, a "social worker" is like a support worker, i.e. provides day-to-day support for the person with ID. This is not the same in the UK, for example, where a social worker of someone with ID would usually only see this person in special meetings or case reviews. This could therefore lead to reader confusion. I suggest clarifying the role of the Dutch social worker in just a short sentence.

We thank the reviewer for pointing this out. We clarified the role of the Dutch social worker briefly through a footnote under table 1 (general overview of the interviewees) on page 27. We added the following information in the footnote:

In the Netherlands, social workers who work in ID care services provide support to people with ID in their daily lives. These social workers usually have an associate degree in socio-pedagogical support.

Reviewer # 1: “2) Background section: I missed the work of Todd here (see above) and think it should be referenced”

We agree that the work of Todd adds valuable background information to this paper. We therefore introduced his work in the background section of the paper (page 5). We added the following information (italics):

Several studies have indicated that ID care professionals have a lack of knowledge and expertise in end-of-life care, for example in pain and symptom management [refs]. Todd interviewed ID care staff and found that although care staff are willing to provide end-of-life care for their clients (with whom they often have strong bonds), they can be very overwhelmed by caring for a dying person. This is amplified by a lack of knowledge and a lack of the kind of support that would enable them to provide this care properly [Todd, 2004, Todd, 2005]. In an earlier study, we found that insufficient expertise among care staff within ID care services often prompts the decision to move a terminally ill client to another care setting [ref].

DISCRETIONARY REVISIONS

Reviewer # 1: “Personally, I would find it more logical and helpful if the summary of research findings, currently the first paragraph of the "Conclusion", was moved to the beginning of the "Discussion" section. (This may be a matter of journal policy and preference though).”

It is indeed journal policy at BMC Palliative Care to end the paper with a main conclusion.
Reviewer # 2 (Ruth Diver)

MINOR ESSENTIAL REVISIONS
Reviewer # 2 : “Throughout the paper the authors have used the term ‘moral values’ to describe the foundational values and attitudes which underlie participants approaches to care. I think the term ‘moral value’ is generally used to refer to a value which defines what a person considers to be universally right or wrong, rather than to the things which they value as important or helpful in a particular situation. I think the term is therefore potentially emotive and is not the best description of what they are discussing. I would suggest ‘moral value’ is replaced with simply ‘value’ or ‘attitude.’ The term is used in lines 37, 59, 73, 97, 140, 165, 199, 217, 232, 249, 267, 327, 328, 330, 370.

We agree with the reviewer that the term ‘moral values’ may raise questions and we changed the term ‘moral values’ to ‘values’.

Line 188 - ‘shower moments’ doesn't really make sense as a term. 'Time taken showering' would read better.

We thank the reviewer for pointing this out. We changed the text to ‘time taken showering’ (page 9).

DISCRETIONARY REVISIONS
Reviewer # 2 : “There is little attention paid to whether the findings here in relation to care givers for people with ID at the end of life are similar to attitudes found in care givers for people without ID at the end of life. This would be an interesting avenue for further research, and it would be helpful to acknowledge it even if you can't do any comparison in this paper.”

In the discussion, we compared the shifts we found to the results of other studies in other client groups in long-term care settings, such as people with dementia and clients in nursing homes and elderly care homes. We agree that a comparison between care givers for people with ID and care givers for people without ID would be an interesting research area. We added the following suggestion for future research to the discussion section (strengths and weaknesses) on page 18:

This study did not explore shifts in the end-of-life care approaches to people without ID. Future research could reveal the extent to which the shifts found in this study match shifts in care approaches among other client groups in long-term care settings, such as people with dementia and residents in nursing homes and elderly care homes.