Author's response to reviews

Title: De-tabooing dying control. A grounded theory study.

Authors:

Hans Thulesius (hansthu@slesius@gmail.com)
Helen Scott (helen.scott@groundedtheoryonline.com)
Gert Helgesson (gert.helgesson@ki.se)
Niels Lynöe (niels.lynoe@ki.se)

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To the editor of BMC Palliative Care

Thank you for responses to our ms submission "De-tabooing control of dying". We have read the reviewers' valuable and challenging comments and will hereby respond to them. We deeply thank the reviewers for reading our ms thoroughly. You have made us improve and refine our text!

Hence we will try to explain how the de-tabooing theory emerged by applying classic grounded theory. HT (first author) presented his first grounded theory of Balancing in palliative cancer care (new refs in ms) at WONCA in Durban 2001 where Luc Deliens claimed "everybody knows that euthanasia is a taboo in the Nordic countries". This became a starting point for the present ms. So colleague and coauthor of prof Cohen - prof Deliens - is one of the very first sources of data for De-tabooing - a good example of the important GT dictum ALL IS DATA! The sources of data in a classic grounded theory have no limits – it can be interviews, informal talks, literature data, survey data, quantitative data, video data. But, All is data is rarely used by GT researchers mostly relying on interview data.

Barney Glaser, the medical sociologist who discovered GT (the GT book Discovery of Grounded Theory has >46000 Google Scholar citations) has since >10 years taught HT and HS (second author) classic grounded theory. HT has translated Doing Grounded Theory into Swedish (Att göra grundad teori, 2010) and is translating Theoretical Sensitivity (another important CGT book). Both HT and HS teach classic grounded theory for PhD students since many years and are rooted in classic grounded theory as taught by Glaser which is often misunderstood having been remodeled by Qualitative Data Analysis researchers borrowing the labels of classic grounded theory procedures and the classic grounded theory jargon but not following the full classic grounded theory package. Classic grounded theory is a scientific paradigm on itself according to Swedish philosopher of science, Jan Hartman. Classic grounded theory -a mostly inductive method - can use any type of data, both qualitative and quantitative; to generate conceptual theories with the purpose to explain what is going on in different areas of study. An important part of classic grounded theory is the
sorting stage, often left out by many researchers claiming to do GT. Sorting and resorting the rich memo data base refines concepts constantly compared with new data as the researcher goes back to the field or to the literature = Theoretical sampling, another GT procedure. So, we have learnt that very few reviewers may fully recognize classic grounded theory since it is rarely applied in most researches claiming to have used the grounded theory method.

Specific comments to Prof Cohen:

"However, I feel that the article suffers from several flaws as a result of which the article does not seem to make a very relevant contribution to the social theory about controlled dying" and

"the discussion should much better address what this paper contributes in terms of insights for the social theory regarding discourses around death and dying, more specifically related to controlled dying."

REPLY: The present study does not intend to challenge or modify a social theory from main stream sociology. Grounded theory is just a method of conceptualization and a CGT product is nothing more than a humble attempt at naming a pattern of behaviour observed in the real world of how people deal with a main concern, in this case dying and the control of dying. And the pattern we observed we choose to call de-tabooing. We have time and time again found that the dying field is immersed with taboos that people are trying to deal with. This is by no means a proven fact but a suggestion of how to name what we have observed and conceptualised from numerous interviews, casual conversations, verbal comments in meetings, open ended written comments in surveys and written comments in Internet chat rooms, newspaper articles and in the scientific literature.

We have now also expanded our Discussion section and included at least a dozen more references

"the article fails to formulate a clear research question"

REPLY: In classic grounded theory the research question is typically "what is going on?" and "what are the participants main concern and how are they continually trying to resolve it".

We have now added this to the introduction

"justify that question, and frame it within a wider academic and social theoretical context."

REPLY: We have now expanded the Discussion section to try to meet this demand bot from prof Cohen and from prof Friedrichsen. The reference list is accordingly much larger.

"the results seem to be a very subjective selection of findings the authors found interesting."

REPLY: This quote illustrates this tangle since a classic grounded theory is never
to be seen as findings. It is a set of carefully generated hypothetical propositions based on a rich data base of memos written from ideas that arise while coding and comparing a large number of field notes. These memos are sorted and resorted and eventually written up in a paper or book.

WE have now added information re what classic grounded theory is in the methods section

"Second, the methods need a clearer explanation and presentation."

REPLY: We have expanded this section and agains emphasize that classic grounded theory can use both qualitative and quantitative data to code and compare what is going on.

"It needs to be explained whether the two surveys used an identical questionnaire"

REPLY: This is now emphasized.

"Judging from the covering letter by the authors I could tell that the issue regarding a lack of clarity in the methods section was also already raised by the editor. The issues raised by the editor (eg source of the data and rationale of the different data sources) has not been addressed adequately)."

REPLY: The issues from the editor’s part dealt with ethics approval for casual conversations and not with the grounded theory method per se. Different data sources is part of the classic grounded theory method as previously mentioned.

"in the presentation of the results, clarify what the source of the results is, ie open comments from the survey or the interviews"

REPLY: This information is now added in the quotes

"How is it possible that you cite a Dutch Law professor in the results section when no Dutch people were included for your interviews (crf methods section). Regarding this passage: the Dutch euthanasia law is 8 pages last time I saw it, not over 90 as indicated in your text."

REPLY: Sorry for this failure. We have now corrected this and added that we actually have respondents from Belgium and the Netherlands

"authors mention that data render support for the hypothesis that truth telling might lead to suicide. This is very careless as it may for instance rather be related to aspects of loss rather than to the terminal diagnosis as such."

REPLY: This hypothesis does not stem from our work but from the literature. We have now expanded this paragraph and added more references.

" the manner in which the authors explain how theory works (ie ‘explaining’ and ‘accounting for variation’ sounds a bit complicit with a rather quantitative and hegemonic biomedical perspective)"
REPLY: This is again just part of classic grounded theory jargon which we claim the right to use...

Specific comments to Prof Friedrichsen:

"The background is more of a history of different aspects of control of dying than a scientific background. I can see the point, but I still miss up to date research and for example sociological theories of death and dying here or papers on euthanasia and physician-assisted suicide. This paper would benefit by adding more science."

REPLY: We have expanded the Discussion section to try to meet these demands

"The purpose could be more stringent and is different in the abstract compared to the one presented in the background. Please, consider my suggestion for a purpose: The purpose is to generate a grounded theory of control of dying focusing on how humans react in relation to questions about euthanasia and physician-assisted suicide."

REPLY: Point taken, we have now added the suggestion to the purpose

"Data collection
There is a great data material, many data collections conducted in different western countries and that is strength in this study, but one problem might be that the purposes have been different for each collection. The two survey purposes: study attitudes to PAS (not euthanasia?) The interview study purpose was?? The interview study purpose was?? The internet-forum purpose: study euthanasia and PAS-discussions (but not attitudes?). The literature study purpose: generate theory on euthanasia and PAS. But the main purpose is to generate a theory and therefore it is possible to have an eagle or helicopter-perspective. The interviews were “carefully recorded in field notes” and that is okay in this type of GT, but I still think it is a weakness as there is no chance to control if the researcher’s notes are what the interviewee really said or if it is an interpretation of what was said. What was the purpose in the interview-study? What questions were posed to the interviewees? I know that the questions change during the process, but still it is important to know the purpose. Where was the interviews conducted? Under what kind of circumstances? What kind of articles was studied? Only from media etc. or scientific papers too? How was these articles found?"

REPLY: The general answer is the classic grounded theory dictum “all is data”, and secondly, a grounded theory is not a reporting of facts but a set of hypotheses in a theory that is more or less relevant, works more or less well, and fits more or less well with the data from which the hypotheses are generated. It is also more or less modifiable when new data enter into the analysis.

Specifically: Yes, the purpose for the surveys were not only to generate grounded theory but also other reports (see references). The purpose of the interviews were definitely to generate theory. The interview questions were not
structured but informal. What the interviewees said was recorded in notes that were then interpreted in memos. Interviews were conducted in public places mainly, scientific and professional meetings etc. The literature studied was both scientific papers and newspaper articles found in many ways, both serendipitely and thru internet searches.

Clarification in the methods section!

"I want to know what kind of data the researchers started to collect and analyse. The two surveys? And then? This is not quite clear even if I try to read the years mentioned in the text under the heading Data collection. I think it is important so that the reader can follow the GT process even better"

REPLY: this is now emphasized in the Methods section

"Please, if possible, give an illustrative example of the process from raw data to different levels of abstractions and then to theory! It would facilitate the reading a lot! The analysis seems to be delimited to de-tabooing, which means that the authors have selected material only to this area. There must be a lot of data material left to analyse? The authors clearly describes that incidents is more important than the number of participants, still they present the number of participants but not the incidents. I think it would be appropriate to present both."

REPLY: Point taken. Examples are provided in an appendix.

Yes, a lot more data may be secondary analysed.

Number of incidents are now mentioned in the Methods

"it is presented papers from different European countries as well as the US (p 9-10), but these papers are not mentioned in the data collection. The papers mentioned in the data collection are particularly from UK. I guess that these papers are part from the literature study, or?"

REPLY: Done so in the Methods

"I miss a conclusion in the end of the discussion."

REPLY: Done.

WE hope that these amendments are satisfactory but are willing to further revise our ms if you so wish

Hans Thulesius, corresponding author