Experiences from international qualitative research: the UNBIASED study

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on behalf of UNBIASED

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Background of UNBIASED

- Netherlands
- Belgium
- UK
- Italy
- Denmark
- Sweden
- Switzerland

2001
2005
2007
2010
**UNBIASED Aim**

- The UNBIASED study (UK Netherlands Belgium International Sedation Study) is a collaboration between research teams in UK, Belgium and the Netherlands.
- Aim of UNBIASED: To examine the experiences of physicians, nurses and bereaved relatives with the use of continuous sedation in end–of–life care for cancer patients and to identify and explain differences in reported practice between UK, Belgian and Dutch practitioners.
**UNBIASED methods**

- In-depth qualitative case study of the use of this practice in the three countries.
  - And related studies (preparatory focus groups, analysis of existing data, review of the literature; ethical analysis)
Methods case studies

- We studied 84 cases involving face-to-face interviews with 57 physicians, 73 nurses and 38 relatives.
- Recruitment to interviews commenced in January 2011 and was completed by May 2012.
- All audiotaped interviews were transcribed verbatim, and all data that could identify the participants were removed.
- The Belgian and Dutch interviews were translated into English by a professional translation agency and checked for accuracy.
What can we learn?
I - Funding

- Funding from several national agencies
  - UK: Economic and Social Research Council
  - BE: Research Foundation Flanders (FWO)
  - BE: Flemish Cancer League (VLK)
  - NL: Netherlands Organization for Scientific Research (NWO)

+ More funding opportunities than only EU

- Differences in grant requirements (like starting date, project duration) may need flexibility of the study (and researchers) → make a good plan, look ahead!
II – Multiple perspectives

- 3 respondent groups: Case study allowed inclusion of physicians, nurses and relatives
- 3 settings: hospitals, domestic home, and palliative care units
- 3 countries: Belgium, the Netherlands, UK
- Mixed methods: Quantitative, qualitative and ethical/philosophical analyses

+ Comparisons of perspectives added value to the research questions
+ Multiple angles for analyses and papers
- It was sometimes difficult to reach sufficient N:
  - To interview physician, nurse and relative per case
  - Somewhat lower number of hospital cases
III - International collaboration

The UNBIASED study is a collaboration between researchers from 3 countries embedded in different disciplines (public health, palliative care, nursing care, oncology, ethics, ..)

University of Southampton, De Montfort University, the University of Sheffield, Lancaster University, Brunel University, University of Nottingham;
Vrije Universiteit Brussel, Ghent University+
Erasmus MC University Hospital Rotterdam, Vrije Universiteit Medical Centre Amsterdam

We found that the practice of palliative sedation varied substantially between the 3 studied countries
+ input from different disciplines and different countries proved very helpful in interpreting practice and results
+ successful collaboration continued in new project (ACTION, about ACP, FP7)
**IV - Publications**

- Case study data only available after long period of data collection
  + Use of existing data bases and other analyses proved very helpful for the PhD students to do preparatory work for the study as well as to be able to have sufficient papers at the end of their PhD trajectory

- Qualitative case study of this size: large amount of data (5000 pages!!)
  + Many opportunities for writing papers (different angles)
  - Difficult to analyze all data at once

- Need to make clear distinctions between the focus of the different papers → think ahead!

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Publications related to UNIBIASED study


Anquinet L, et al. GP’s and nurses’ descriptions of their collaboration in continuous sedation until death at home. In press.


Conclusion

Wise people see trouble ahead and avoid it

KEEP CALM AND COLLABORATE