

A COMPARATIVE STUDY OF THE VIEWS REGARDING PALLIATIVE SEDATION IN CHRISTIAN AND INDIAN RELIGIONS

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Project abstract:

Palliative sedation is an end-of-life treatment aimed at relieving the suffering caused by refractory symptoms in terminally ill patients, i.e. symptoms that cannot be relieved by any means other than consciousness reduction. Palliative sedation has been the subject of often heated social and academic debate since the 1990s. However, until now, little attention has been paid to the specific views and attitudes that the world's religions present with respect to this practice. Considering that religion can have a remarkable influence on the attitudes that both palliative care patients and their families and caregivers adopt towards palliative sedation, it is important to know what religious traditions actually say or teach about the practice. Such a goal becomes especially relevant in the context of a country and continent that in recent decades has become much more multi-cultural and multi-religious. At present, much is known and much has been written about religious views on certain end-of-life treatment decisions such as euthanasia, pain control, and withholding or withdrawing life-sustaining treatments (e.g., artificial hydration and nutrition). Nonetheless, palliative sedation, being a fairly recent specialized development in palliative care, has so far received only limited attention from the part of religious authorities (and also from specialists themselves). Considering such a gap in palliative care research, the present project aims to shed light on the normative ethical attitudes presented by the major Christian and Indian religious traditions towards palliative sedation. To this end, the project consists of three parts. (1) First, a comprehensive database on the views of Christian and Indian religious traditions on palliative sedation will be developed through a systematic literature study. All available empirical studies on the role of religion in palliative sedation, as well as the teachings of religious authorities and religious specialists on this topic, will be collected and reviewed. Since most religious traditions have not yet officially proclaimed their teachings and positions on palliative sedation specifically, (2) in a second phase, leading authorities and specialists from each tradition will be interviewed about their position on palliative sedation (semi-structured interviews, grounded theory approach). This part of the project will focus specifically on religious authorities in Belgium. (3) Finally, once a clear picture of the (variety of) views of each tradition has been obtained, the perspectives of both religious traditions (Christianity and Indian religions) will be compared.

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RESEARCH DATA SUMMARY

List and describe all datasets or research materials that you plan to generate/collect or reuse during your research project. For each dataset or data type (observational, experimental etc.), provide a short name & description (sufficient for yourself to know what data it is about), indicate whether the data are newly generated/collected or reused, digital or physical, also indicate the type of the data (the kind of content), its technical format (file extension), and an estimate of the upper limit of the volume of the data.

Dataset name / ID	Description	New or reuse	Digital or Physical data	Data Type	File format	Data volume	Physical volume
		<i>Indicate: N(ew data) or E(xisting data)</i>	<i>Indicate: D(igital) or P(hysical)</i>	<i>Indicate: Audiovisual Images Sound Numerical Textual Model Software Other (specify)</i>		<i>Indicate: <1GB <100GB <1TB <5TB >5TB NA</i>	
Literature study							
Protocol_literature search	Systematic protocol description about how to conduct the search of the literature study	N	D	T	.docx	< 100 KB	/
Reports retrieved	Excel file with number of reports retrieved per query string and database	N	D	N+T	.xlsx	< 100 KB	/
References lists pre-screening	Lists of references retrieved from the databases	E	D	N+T	.ris	< 500 KB	/
References selection	Lists of references selected and discarded (with reasons)	N	D	N+T	Accessible in the software Rayyan	/	/
References list post-screening	List of references selected for the study	E	D	N+T	.ris	< 500 KB	/
Data extraction sheet	Excel file with data extracted from the selected references	N	D	N+T	.xlsx	1-2 GB	/
Codebook_literature study	NVivo file with the analysis of the selected references	N	D	T	.nvp	< 5 GB	/
Empirical study							
Protocol_Interviews	Instructions about how to	N	D	T	.docx	< 100 KB	/

	conduct the interviews, together with pre-defined questions/topics to address and the consent form for the participants to sign.						
Audio recordings	Audio recordings of the interviews with religious authorities and specialists	N	D	S	.mp3	Files of about 105 interviews < 500 GB	/
Transcripts	Interview transcripts	N	D	T	.docx	8-10 GB	/
Interview notes	Notes taken during interviews	N	P	T	On paper	/	Four notebooks
Interview notes_dig	Digitalized version of the notes taken during the interviews	N	D	T	.docx	1-2GB	/
Codebook_Interviews	NVivo file with the analysis of the interviews	N	D	T	.nvp	< 500 GB	/

If you reuse existing data, please specify the source, preferably by using a persistent identifier (e.g. DOI, Handle, URL etc.) per dataset or data type:

For the literature study, reports will be searched in the following databases:

- AnthroSource: <https://anthrosource.onlinelibrary.wiley.com/>
- ATLA Religion Database: <https://www.ebsco.com/products/research-databases/atla-religion-database-atlaserials-plus>
- Bibliography of Asian Studies: <https://www.ebsco.com/products/research-databases/bibliography-asian-studies>
- CINAHL: <https://www.ebsco.com/es/productos/bases-de-datos/cinahl-database>
- Cochrane Library: <https://www.cochranelibrary.com/>
- EMBASE: <https://www.elsevier.com/products/embase>
- Index Theologicus: <https://ixtheo.de/>
- Index Religiosus: <http://cpps.brepolis.net/ir/search.cfm>
- JSTOR: <https://www.jstor.org/>
- MEDLINE: <https://www.wolterskluwer.com/en/solutions/ovid/ovid-medline-901>
- OpenDissertations: <https://opendissertations.org/>
- OpenGrey: <https://opengrey.eu/>
- Philpapers: <https://philpapers.org/>
- PsycARTICLES: <https://www.apa.org/pubs/databases/psycarticles>
- PubMed: <https://pubmed.ncbi.nlm.nih.gov/>

- SciVerse: <https://www.researchinformation.info/product/sciverse>
- ScienceDirect: <https://www.sciencedirect.com/>
- Scopus: <https://www.scopus.com/search/form.uri?display=basic#basic>
- The Philosopher's Index: <https://www.ebsco.com/products/research-databases/philosophers-index>
- WorldCat: <https://search.worldcat.org/>

A search will be also conducted in the following interfaces:

- Google: <https://www.google.com/>
- Google Scholar: <https://scholar.google.com/>
- Limo: <https://kuleuven.limo.libis.be>
- ProQuest: <https://www.proquest.com/>
- Web of Science: <https://www.webofscience.com/wos/woscc/basic-search>

Each report retrieved from the databases and interfaces will be listed with its specific bibliographic reference in .ris format. The DOI of each report will be part of the information collected in the .ris documents.

Are there any ethical issues concerning the creation and/or use of the data (e.g. experiments on humans or animals, dual use)? If so, refer to specific datasets or data types when appropriate and provide the relevant ethical approval number.

- Yes, human subject data (Provide SMEC or EC approval number below)

The interview study will be submitted to the SMEC for ethical approval in January 2025 (approximate date, could change).

Will you process personal data? If so, please refer to specific datasets or data types when appropriate and provide the KU Leuven or UZ Leuven privacy register number (G or S number).

- Yes (Provide PRET G-number or EC S-number below)

Personal data will be processed in the following datasets: Audio recordings, Transcripts, Interview notes, Interview notes_dig and Codebook_interviews.

- The audio recordings will be deleted after transcription.
- Each participant will be assigned a pseudonym that will be used when manipulating the data.
- Any direct identifier of the participants' personal data will be removed from the interview transcripts, interview notes and codebook.

The KU Leuven privacy register number will be obtained after ethical approval submission (see previous point).

Does your work have potential for commercial valorization (e.g. tech transfer, for example spin-offs, commercial exploitation, ...)? If so, please comment per dataset or data type where appropriate.

- No

Do existing 3rd party agreements restrict exploitation or dissemination of the data you (re)use (e.g. Material or Data transfer agreements, Research collaboration agreements)? If so, please explain in the comment section to what data they relate and what restrictions are in place.

- No

Are there any other legal issues, such as intellectual property rights and ownership, to be managed related to the data you (re)use? If so, please explain in the comment section to what data they relate and which restrictions will be asserted.

- Yes

Yes, the reuse of reports retrieved from databases in the literature study. In order to avoid plagiarism, the data extracted from each report will be cited properly.

DOCUMENTATION AND METADATA

Clearly describe what approach will be followed to capture the accompanying information necessary to keep data understandable and usable, for yourself and others, now and in the future (e.g. in terms of documentation levels and types required, procedures used, Electronic Lab Notebooks, README.txt files, codebook.tsv etc. where this information is recorded).

The datasets from the two studies (literature study and interviews) will be stored in clearly labelled folders in KU Leuven's OneDrive. In the label of each file will be indicated: content description, date and initials of the creator (e.g., Protocol_literature search_12 March 2024_MGA).

In addition, as it is listed in the data summary (see table above), each study will be accompanied with a protocol, which clearly describes the steps taken during study conduction, and with the codebook used for the qualitative analysis. Both protocols (literature study and interviews) will be saved as .docx and as .txt files, and both codebooks (literature study and interviews) will be saved as .nvp and as .txt files.

Regarding pseudonymized data, in the case of the interview study, an excel file (.xlsx) with the personal data of the participants connected to their corresponding pseudonyms will be kept separately in a Share Drive being only accessible to the two PhD students involved in the project and the supervisor. The steps taken to remove any direct identifiers in the interviews' data will also be described in the interviews' protocol.

**Will a metadata standard be used to make it easier to find and reuse the data?
If so, please specify which metadata standard will be used.**

If not, please specify which metadata will be created to make the data easier to find and reuse.

- No

See above.

DATA STORAGE & BACK-UP DURING THE RESEARCH PROJECT

Where will the data be stored?

- Shared network drive (J-drive)
- OneDrive (KU Leuven)

The responsible person will be Prof. dr. Bert Broeckeaert, the supervisor of this C1 project.

How will the data be backed up?

- Standard back-up provided by KU Leuven ICTS for my storage solution

Is there currently sufficient storage & backup capacity during the project?

If no or insufficient storage or backup capacities are available, explain how this will be taken care of.

- Yes

How will you ensure that the data are securely stored and not accessed or modified by unauthorized persons?

OneDrive documents will be shared only among the supervisor and PhD students involved in the research project. Documents stored in the Shared Drive will only be accessible to the PhD students and the supervisor. In case documents are shared outside of the research project (e.g., research team, research unit), this will be done with restricted access (shared via Belnet FileSender: <https://filesender.belnet.be/>), editing rights (view-only) and pseudonymized (if documents are from the interview study). The personal data from the participants will **not** be shared.

What are the expected costs for data storage and backup during the research project? How will these costs be covered?

None.

DATA PRESERVATION AFTER THE END OF THE RESEARCH PROJECT

Which data will be retained for 10 years (or longer, in agreement with other retention policies that are applicable) after the end of the project?

In case some data cannot be preserved, clearly state the reasons for this (e.g. legal or contractual restrictions, storage/budget issues, institutional policies...).

- All data will be preserved for 10 years according to KU Leuven RDM policy

After transcription, all audio recordings will be destroyed. Only pseudonymized data will be stored (separated from the codes connecting it to personal data).

Where will these data be archived (stored and curated for the long-term)?

- KU Leuven RDR

The members of the research group/unit have access to the data with the permission of the supervisor.

What are the expected costs for data preservation during the expected retention period? How will these costs be covered?

None.

DATA SHARING AND REUSE

**Will the data (or part of the data) be made available for reuse after/during the project?
Please explain per dataset or data type which data will be made available.**

- Yes, as restricted data (upon approval, or institutional access only)

If access is restricted, please specify who will be able to access the data and under what conditions.

During the project, the data will be accessible only to both PhD researchers, Jonathan Lambaerts and Mar Gil Álvarez, and the responsible supervisor of the C1 project Prof. dr. Bert Broeckaert.

After the project, the data might be reused by research team/unit members with the supervisor's approval only.

Are there any factors that restrict or prevent the sharing of (some of) the data (e.g. as defined in an agreement with a 3rd party, legal restrictions)?

Please explain per dataset or data type where appropriate.

- Yes, privacy aspects

Participants' personal data (name, contact information, age, gender) will not be shared due to privacy reasons.

Where will the data be made available?

If already known, please provide a repository per dataset or data type.

- KU Leuven RDR (Research Data Repository)

When will the data be made available?

- Upon publication of research results

Upon publication of research results: paper publications, seminars, conference proceedings and workshops.

Which data usage licenses are you going to provide?

If none, please explain why.

- Other (specify below)

Custom KU Leuven license.

The access to participant's personal data will be restricted. Access will be provided only with the supervisor's (Pr. dr. Bert Broeckaert) permission.

Do you intend to add a persistent identifier (PID) to your dataset(s), e.g. a DOI or accession number? If already available, please provide it here.

- Yes, a PID will be added upon deposit in a data repository

What are the expected costs for data sharing? How will these costs be covered?

The potential costs for data sharing (Open Access, workshops' organization, etc.) will be covered with the budget of the project.

RESPONSIBILITIES

Who will manage data documentation and metadata during the research project?

The two PhD researchers appointed to the C1 research project, Jonathan Lambaerts and Mar Gil Álvarez.

Who will manage data storage and backup during the research project?

The two PhD researchers appointed to the C1 research project, Jonathan Lambaerts and Mar Gil Álvarez.

Who will manage data preservation and sharing?

The supervisor of this C1 BOF project, Prof. dr. Bert Broeckaert.

Who will update and implement this DMP?

The two PhD researchers appointed to the C1 research project, Jonathan Lambaerts and Mar Gil Álvarez.