
I am so tired of existing: Clarifying the complex and multilayered experience of tiredness of life by a multi-informant interdisciplinary approach (ClarEToL)

A Data Management Plan created using DMPonline.be

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Project abstract:

The ClarEToL project aims to achieve a thorough understanding of how tiredness of life (ToL) is experienced by both elderly people and their informal and professional caregivers. The lived experiences of the people suffering from ToL and their relatives are lacking any scientific attention. Through in-depth semi-structured interviews with both nursing home residents and their (in)formal caregivers, ClarEToL's goal is to deepen our understanding about the phenomenon by taking all relevant perspectives into account. As the problem seems to be pressing in nursing homes, an environment with both a very high average age and a severe care-dependency, this project aims to focus on the specific context of residential care facilities.

This DMP application describes the first work package of the ClarEToL project, which includes four sub-studies. All four studies use a qualitative in-depth design but target different populations: nursing home residents (study 2A), their informal carers (study 2B) and their formal carers (study 2C).

The study has a twofold focus: gaining knowledge on the lived experience in the present (S2 A, B and C) as well as on the memories of lived experience in the past (study 1). This will provide information on how older adults and their carers experience(d) tiredness of life in the contemporary society as well as in the past.

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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>	Indicate: Audiovisual Images Sound Numerical Textual Model SOftware Other (specify)		Indicate: <1GB <100GB <1TB <5TB >5TB NA	
S1A	Historical data: interviews with relatives of (deceased) elderly people	N	D	S	.mp3	Files of about 15 interviews (<100 GB)	/
	Transcripts	N	D	T	.docx	1-2 GB	/
	Personal and fieldnotes on interviews	N	P	T	On paper		Written in a Notebook
	Personal and fieldnotes on interviews	N	D	T	.pdf, .jpg (pictures of the notes), .docx	Notes of 15 interviews, saved in a digital format <1 GB	
S1B	Historical data: interviews with professional caregivers	N	D	S	.mp3	Files of about 15 interviews (< 100 GB)	
	Transcripts	N	D	T	.docx	1-2 GB	
	Personal and fieldnotes on interviews	N	P	T	On paper		Written in a notebook
	Personal and fieldnotes on interviews	N	D	T	.pdf, .jpg (pictures of the notes), .docx	Notes of 15 interviews, saved in a digital format <1 GB	
S2A	Current data: interviews with nursing home residents (NHR)	N	D	S	.mp3	Files of about 30 interviews with NHR (< 100 GB)	
	Transcripts	N	D	T	.docx	1-2 GB	
	Coding of transcripts	N	D	T	.nvp (codes given in Nvivo)	< 100 GB	
	Personal and fieldnotes on interviews	N	P	T	On paper		Written in a notebook
	Personal and fieldnotes on interviews	N	D	T	.pdf, .jpg (pictures of the notes), .docx	Notes of 15 interviews, saved in a digital format <1 GB	
S2B	Current data: interviews with informal caregivers	N	D	S	.mp3	Files of about 15 interviews (<100 GB)	

	Transcripts	N	D	T	.docx	1-2 GB	
	Coding of transcripts	N	D	T	.nvp (codes given in Nvivo)	< 100 GB	
	Personal and fieldnotes on interviews	N	P	T	On paper		Written in a notebook
	Personal and fieldnotes on interviews	N	D	T	.pdf, .jpg (pictures of the notes), .docx	Notes of 15 interviews, saved in a digital format <1 GB	
S2C	Current data: individual interviews with health care practitioners (HCP) and/or Focusgroups	N	D	S	.mp3	Files of individual interviews and/or focusgroups (<100 GB)	
	Transcripts	N	D	T	.docx	1-2 GB	
	Coding of transcripts	N	D	T	.nvp (codes given in Nvivo)	< 100 GB	
	Personal and fieldnotes on interviews	N	P	T	On paper		Written in a notebook
	Personal and fieldnotes on interviews	N	D	T	.pdf, .jpg (pictures of the notes), .docx	Notes of 15 interviews, saved in a digital format <1 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:

Datasets of the interviews (S2A-B-C) will be reused in a second phase of the project.

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)

We have submitted this project for ethical review (G-2023-6418), but have not yet received a decision.

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)

All datasets (S1A, S1B, S2A, S2B, S2C) include personal data, namely personal and emotional testimonies.

PRET: G-2023-6418

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

NA

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.

- No

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).

In general, for each study meta-data will be available and stored on the shared drive (Teams, Onedrive) of KU Leuven.

Historical datasets S1A and S1B: when sharing the pseudonymised data on KU Leuven RDR (in closed access), we will a separate README.txt file, explaining briefly the informed consent process, a short summary of the content of the data, the context in which the interviews took place, information about file formats. Also steps taken to remove direct identifiers in the data will be described.

Current datasets S2A, S2B, S2C: we will provide general information on methodology and the informed consent process in the preregistration form, as well as the codebook we used for the qualitative analysis process.

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)
- Personal network drive (I-drive)
- OneDrive (KU Leuven)
- Sharepoint online

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

The data will be stored on the university's central servers with automatic daily back-up procedures.

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

S1A and S1B: Storage at the One drive cloud service provided by the Faculty of Arts (2 TB storage free of charge). This storage space is safe and automatically backed-up, and allows for extra protection of sensitive data, such as Multi Factor Authentication and Conditional Access functions, so that the historical researcher alone can access the data before anonymisation. The data will be anonymised with Cubase, distorting the voice and bleeping any identifiable information.

S2A, S2B, S2C: The data of the current experiences (S2) will be stored at secure KU Leuven drives (I-/J-drive). After data collection, the data will be pseudonymized by the doctoral researcher. The name of the participant will be coded by means of a unique, randomly generated code. Similarly, other potentially identifying information (e.g., names of places or relatives) will be replaced with a unidentifiable information (e.g., "medium-sized city"; "older brother"). The identification file that contains the unique code and name will be managed externally and is stored on a special encrypted disk that is managed by the database managers of the research unit SCenO – psychology (prof. J. Spilt & prof. K. Luyckx), so separated from the research data. The drive (CODES share) is provided by the IT service from the faculty of Psychology and Educational Sciences and fulfills the conditions of the data management of the pseudonymised data. All audio recordings will be destroyed once the data is analysed.

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

None:

S1A, S1B: 2TB free of charge storage provided by the Faculty of Arts is enough for this project

S2A, S2B, S2C: As stated above, we do not expect extra costs for data storage. In case we need to extend the storage capacity, costs will be covered by the credits of the supervisors and/or the bench fees from the PhD students.

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
- Certain data cannot be kept for 10 years (explain below)

S2A, S2B, S2C: after analysing the data, all audio recordings will be destroyed. Only pseudonymised data will be stored (separated from the codes connecting it to personal data) at the shared network drive (J-drive) of the research unit SCenO of psychology.

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

- Shared network drive (J-drive)
- KU Leuven RDR
- Other (specify below)

S1A, S1B: As it is obligatory for phd students at the Faculty of Arts to use a data repository, the historical data will be shared in closed access in RDR (see above). Additionally, if the participant gives his/her consent for preservation, the interview will be stored in the oral history repository of KADOC (via informed consent letter).

S2A, S2B, S2C: after analysing the data, all audio recordings will be destroyed. Only pseudonymised data will be stored (separated from the codes connecting it to personal data) at the shared network drive (J-drive) of the research unit SCenO of psychology.

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 embargoed data (temporary restriction)
- No (closed access)
- Yes, as restricted data (upon approval, or institutional access only)
- Yes, as open data

S1A, S1B: depending on the participant's choice in informed consent letter, audiotapes will be donated to KADOC.

S2A, S2B, S2C: participants who consent to using excerpts of the interview for scientific publication. Full transcripts (including personal information, codes and fieldnotes) cannot be shared due to privacy issues. Pseudonymised transcripts might be made available by motivated request.

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

S1A, S1B: depending on what the participant chose in informed consent letter; i.e. for scientific purposes only or in case the interviewee wants to evaluate case by case.

S2A, S2B, S2C: upon motivated request by email. Data availability will be stated in the preregistration of each study on OSF. If access is allowed, pseudonymised data will be shared using a secured email-program.

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, ethical aspects
- Yes, privacy aspects

All datasets contain personal and sensitive information of a vulnerable group, so we have an ethical and legal obligation to protect (and not share) some of the data (specifically S1A, S2A, S2B, S2C) e.g transcripts and audio recordings.

When a participant indicates in the informed consent letter not to share the data, we will respect this restriction.

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)
- Other data repository (specify below)

OSF (Open Science Framework)

When will the data be made available?

- Upon publication of research results

Which data usage licenses are you going to provide?

If none, please explain why.

- Data Transfer Agreement (restricted data)
- CC-BY 4.0 (data)

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?

None, RDR is free of charge, as well as OSF

Responsibilities

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

S1A, S1B: Stefanie Meul and supervisors (Kaat Wils and Tinne Claes)

S2A, S2B, S2C: Hannah Thys, Elisa Van Wiele, Stefanie Meul and supervisor (Jessie Dezutter)

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

S1A, S1B: Stefanie Meul

S2A, S2B, S2C: Hannah Thys, Elisa Van Wiele, Stefanie Meul

Who will manage data preservation and sharing?

S1A, S1B: Kaat Wils, Tinne Claes and Stefanie Meul

S2A, S2B, S2C: Hannah Thys, Elisa Van Wiele and Jessie Dezutter

Who will update and implement this DMP?

The PhD-students Hannah Thys, Elisa Van Wiele and Stefanie Meul