Plan Overview

A Data Management Plan created using DMPTuuli

Title: Psychosocial and Spiritual Needs of Children with Terminal Cancer and Their Families: A Comparative Study of Social Work Responses in China and Finland

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Project abstract:

Psychosocial and spiritual support is a core component of pediatric palliative care. In Mainland China, pediatric palliative care and social work practice are still in the early stages of development, leading to the neglect of psychosocial and spiritual needs. In contrast, Finland has established a more comprehensive system and practice framework in this field.

This study aims to explore the psychosocial and spiritual needs of children with terminal cancer and their families in Mainland China, and to analyze the roles and challenges of current social work practices in addressing these needs. Through a comparative study with Finland’s well-developed social work practices, the research seeks to identify culturally adaptable and applicable approaches to promote the development of a more empathetic, systematic, and professionally supported pediatric palliative social work model in the Chinese context, providing more holistic and dignified end-of-life care for children and their families.

A qualitative research design will be employed, combining descriptive and comparative methods. Semi-structured interviews and document analysis will be conducted with parents, social workers, and professionals from Finland to collect diverse perspectives, with thematic analysis used for cross-cultural comparison and synthesis.

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Psychosocial and Spiritual Needs of Children with Terminal Cancer and Their Families: A Comparative Study of Social Work Responses in China and Finland

1. General description of the data

1.1 What kinds of data is your research based on? What data will be collected, produced or reused? What file formats will the data be in? Additionally, give a rough estimate of the size of the data produced/collected.

The research data will be based on both primary and secondary data sources. Primary data will be gathered through semi-structured interviews. Secondary data will be gathered from Finnish policies, guidelines, and professional frameworks in pediatric psychosocial care/social work, in order to contextualize and inform the cross-cultural comparison. Under primary data sources, semi-structured interviews will be conducted in Chongqing, Beijing, Shenzhen, and Shanghai in China, and in Kuopio, Turku, Helsinki, and Tampere in Finland. Participants will be drawn from family members of end-of-life children from 4 hospitals in China (10–15 parents per hospital, approx. 40–60 parents in total). Data gathered will be stored using common file types that allow for open data formats such as docx, pdf, excel, mp3, mp4, and txt. The total size of the research data, mainly consisting of audio-recorded interviews, verbatim transcripts, and policy documents, is expected not to exceed 3 GB.

1.2 How will the consistency and quality of data be controlled?

For data collection from families of pediatric patients, data source triangulation will be employed by gathering information from different times, locations, and individuals. In addition, methodological triangulation will be applied by using interviews and document analysis.

For the data related to social workers, information will be collected through individual interviews, as well as from various hospitals and professional roles, to ensure the consistency and quality of the data gathered. Since the researcher speaks and understands the Sichuanese mandarin and Chinese languages of Chongqing and Beijing, respectively, communication and information gathering will be effective and ensure the consistency of data. The interviews conducted in the Finland region will primarily be carried out in English, with Finnish–English translation provided as needed.

What’s more, transcripts from audio interviews will undergo a double check with notes taken during the interviews and with external actors (e.g., faculty members and colleagues) to ensure consistency and accuracy of information obtained. In addition, cross-national peer debriefing will be conducted with experts from both China and Finland to ensure cultural sensitivity and minimize cultural bias in data interpretation.

Data	Is the data collected, produced, or reused	File format	File size	Sensitive data(Y/N)	What part of the data can be made openly available	Who owns the data/planned licenses
Primary data: Interviews	To be collected	Docx, txt, mp3, and mp4	0.5 GB	Yes	Metadata-that will not expose the participant to danger	The Ph.D. researcher
Focus group discussion	To be collected	Docx, txt, mp3, and mp4	0.5 GB	Yes	Metadata-that will not expose the participant to danger	The Ph.D. researcher
Observation	To be collected	Mp4/video, audio recordings	0.5 GB	Yes	Metadata-that will not expose the participant to danger	The Ph.D. researcher
Secondary data: documents from social worker	To be collected	Docx, excel, pdf	0.5 GB	Yes	Metadata-that will not expose the participant to danger	Social workers own the data. But adapted data owned by the Ph.D researcher
Secondary data: Journal articles, published and unpublished theses and books, policy papers, print and electronic media, and internet sources	To be re-used	txt, online	0.5 GB	No	Metadata-that will not expose the participant to danger	The original authors and agencies own the data. But adapted data will be owned by the Ph.D. researcher

2. Ethical and legal compliance

2.1 What legal issues are related to your data management? (For example, GDPR and other legislation affecting data processing.)

This study involves human participants and may address sensitive topics, especially for participants from families. As such, ethical responsibility and adherence to legal regulations are essential for safeguarding participants' privacy and ensuring the integrity of the research. Ethical principles, including the commitment to “do not harm,” will be upheld through compliance with the General Data Protection Regulation (GDPR) and approval from the relevant faculty and ethics committee. The research will be guided by principles such as transparency, informed consent, voluntary participation, confidentiality, anonymity, reflexivity, and critical distance. Any information related to underaged children, including siblings, will be strictly anonymized and coded. No direct data will be collected from minors; only information volunteered by parents will be included. Any information that may pose a risk to participants will be anonymized, renamed, or deleted after its use to protect their identity.

2.2 How will you manage the rights of the data you use, produce and share?

The doctoral researcher will retain sole ownership of the research data and will share it with their supervisor(s) throughout the entire research process. Due to privacy and ethical restrictions, the research data will not be made publicly available. Data will only be stored in the University of Eastern Finland's secure LocalDrive workspace, and the first author may provide access upon reasonable request. Any reuse of the research data should be properly acknowledged and cited, particularly for studies related to social welfare, child protection, and end-of-life care policies, especially in the context of PPC practice and research at local, national, and global levels.

3. Documentation and metadata

3.1 How will you document your data in order to make it findable, accessible, interoperable and re-usable for you and others? What kind of metadata standards, README files or other documentation will you use to help others to understand and use your data?

To ensure that the research data is findable, accessible, interoperable, and reusable (FAIR), all non-sensitive data will be documented systematically and made openly accessible. Comprehensive metadata—including administrative, structural, and descriptive metadata—will accompany the datasets to enhance discoverability and usability. The study will adopt the Data Documentation Initiative (DDI) metadata standard, which is well-suited for documenting social science and qualitative data.

In addition, each dataset will be accompanied by README files that clearly describe the data structure, variables, collection methods, context of the study, and any relevant codes or classifications used. These files will also outline any limitations or considerations for secondary use. This documentation will help ensure that other researchers, policymakers, and stakeholders can understand, evaluate, and responsibly reuse the data in ways that contribute to knowledge on psychosocial support, spiritual care, and social work in pediatric palliative care.

4. Storage and backup during the research project

4.1 Where will your data be stored, and how will the data be backed up?

A key component of field research is the secure storage and reliable backup of data. All research data, including both sensitive and non-sensitive materials, will be securely stored in the University of Eastern Finland's (UEF) high-security LocalDrive workspace with controlled access rights. In addition, a password-protected external hard drive will be used to store backups; this will be kept in the researcher's locked safe and will not be accessible to anyone else.

Audio recordings of interviews will be deleted immediately after verbatim transcription, and transcripts will be pseudonymized to protect participants' identities.

Only anonymized metadata and aggregated findings may be deposited for reference. Data will be stored securely for five (5) years after the publication of the dissertation, after which it will be permanently destroyed using secure deletion methods.

4.2 Who will be responsible for controlling access to your data, and how will secured access be controlled?

The PhD researcher will serve as the primary data controller and will be responsible for day-to-day management of the research data. Access to the UEF LocalDrive workspace and the encrypted external backup drive will be restricted to the researcher only. Supervisors may review anonymized datasets and aggregated findings for academic purposes but will not have access to identifiable data.

All access rights will be strictly managed in accordance with the University of Eastern Finland's data protection policies and GDPR requirements. Identifiable information (such as contact details) will be stored separately from research data in a password-protected file, accessible only to the lead researcher. The key linking code will be stored securely by the lead researcher and will not be shared with any third party.

5. Opening, publishing and archiving the data after the research project

5.1 What part of the data can be made openly available or published? Where and when will the data, or its metadata,

be made available?

Due to privacy and ethical restrictions, the research data—including interview transcripts and audio recordings—will not be made openly available. Only anonymized metadata and aggregated findings will be published in academic journals, conference presentations, and stakeholder reports.

Research data will be stored securely in the University of Eastern Finland's high-security LocalDrive workspace, with a password-protected external backup drive kept by the researcher. Access to identifiable data will be strictly limited to the PhD researcher.

In line with the data management plan, the anonymized datasets may be provided upon reasonable request to the first author, subject to ethical review and approval, but they will not be deposited in public repositories.

5.2 Where will data with long-term value be preserved, and for how long?

The research data will be securely stored in the University of Eastern Finland's high-security LocalDrive workspace, with an additional password-protected external hard drive backup kept by the researcher in a locked safe. In accordance with the data management plan, all data will be permanently destroyed within five (5) years after the publication of the dissertation.

6. Data management responsibilities and resources

6.1 Who (for example role, position, and institution) will be responsible for data management?

Both the Ph.D. researcher and the University of Eastern Finland (UEF) will be responsible for data management. The Ph.D. researcher, as the primary investigator, will oversee the day-to-day handling, organization, and ethical use of the data throughout the project. The University of Eastern Finland will provide institutional support by ensuring access to secure storage infrastructure, data protection compliance, and long-term archiving services.

6.2 What resources will be required for your data management procedures to ensure that the data can be opened and preserved according to FAIR principles (Findable, Accessible, Interoperable, Re-usable)?

To ensure that the data management procedures align with the FAIR principles, the research project will rely on the high-security LocalDrive workspace and data protection infrastructure provided by the University of Eastern Finland (UEF). In addition, a password-protected external hard drive, kept securely by the researcher, will be used for backup. These institutional resources will ensure metadata creation, secure storage, and preservation of research data during the project. Due to privacy and ethical restrictions, the datasets will not be publicly available. All anonymized data stored in the UEF LocalDrive workspace and external hard drive will be permanently destroyed within five (5) years after the publication of the dissertation.