Plan Overview

A Data Management Plan created using DMPonline

Title: A multi-site case study to explore the experiences clinicians, patients and informal carers' understanding of complex community palliative care needs at end-of-life.

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Template: DCC Template

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Project abstract:

Introduction: The term 'complex palliative care' is used to categorise people with life limiting illnesses who experience increased severity of symptoms. In practice, the term has been ambiguously communicated and inconsistently defined, and there is no uniformity in referring patients to specialist palliative care services. Clinicians' categorisation of patients as complex, and the patients' understanding of the needs as 'complex' has not been studied. Understanding and addressing these issues may reduce palliative care inequalities and facilitate a good death.

Aim: To explore what is known about specialist palliative care clinicians', informal cares' and patients' experiences of categorising or being categorised as having complex palliative needs and develop insights on understanding and improving delivery of community specialist palliative care.

Methods

Design: Multi-phase qualitative study using social constructivist theory. ***Setting:*** Hospices providing adult palliative and end-of-life care in the West Midlands, United Kingdom. ***Participants:*** Purposive sample of adults with life limiting illness, informal carers and palliative care clinicians. ***Data collection:*** Multi-site case studies where participants will be interviewed and clinicians observed by the patient's bedside and in multi-disciplinary team meetings. ***Analysis:*** Ethnographic analysis will be used to analyse observations, and reflective thematic analysis will be used to analyse interviews. A cross-case analysis of the case studies will be done. ***Implications:*** The research findings will be disseminated through peer reviewed journals and research conferences. The knowledge will help palliative care understand broad definitions of complex palliative care needs held by clinicians and patients, be useful for planning patient-centred care and enhance equitable access to specialist palliative care.

ID: 160724

Start date: 01-01-2025

End date: 31-12-2027

Last modified: 29-01-2025

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A multi-site case study to explore the experiences clinicians, patients and informal carers' understanding of complex community palliative care needs at end-of-life.

Data Collection

What data will you collect or create?

Data collection

Data will be collected from interviews with clinicians, patients and informal carers. Interviews will be audio recorded on MS Teams private meetings app. Interviews will be transcribed and analysed using NVIVO software.

Data will also be collected from bedside observations and and multi-disciplinary meetings inform of fieldnotes and coded discrete behaviours.

Data will be coded in order to protect the participants.

Data storage

Data will be stored on a University of Warwick password protected computer drive. Audio recorded interviews will be securely stored and then deleted after the transcription. Field notes will be transferred onto a computer drive and the paper form will be securely shredded

Pseudonymised research data will only be accessed by the principal investigator, the two supervisors and the University of Warwick approved administrator.

Data format: Plain text and diagrams

How will the data be collected or created?

Methodologies

Participant demographic data and consent forms will be digitalised

Face-to-face interviews and non-participatory observations. Member checking of the collected records will be done to confirm the recorded information.

Data will be peer reviewed by supervisors

Data structure

Data will be store in folders and version control will be used

Documentation and Metadata

What documentation and metadata will accompany the data?

Data will be stored as text files.

Pretty Manyimo will maintain a Statement of Activities and Events throughout the research period.

Ethics and Legal Compliance

How will you manage any ethical issues?

Ethics approval

I have made a BSREC application and I am awaiting an approval to start data collection. I will also apply for approval from any participating hospice's Research Governance.

I will apply for local governance approval from the participating hospices before I start data collection.

I will receive written and verbal informed consent from the participants and allow them to ask questions, and date the consent:

- before and during data collection
- to share and reuse data.
- to preserve interviews and observations data up to 10 years after publication, and preserve consent forms and participants' demographic data for up to three month after publication.

Participants' demographic information, personal data will be-identified and stored separately from the research data. Research data will be pseudonymised and the key to identification will be stored separately.

How will you manage copyright and Intellectual Property Rights (IPR) issues?

The University of Warwick own the copyright and IPR of the data that will be collected.

Data will not be shared outside the University of Warwick, and will be restricted to publishing.

Storage and Backup

How will the data be stored and backed up during the research?

Every research activity and what has been discovered will be stored on the University of Warwick institutional server or repository (M; drive). The type of data records that will be stored are digital and hard copies will be temporarily stored, digitalised and securely destroyed.

Data will be retained according to the university's data retention policy, i.e research data will be retained for 10 years after publication, reviewed and then deleted by the approve University of Warwick administrator.

Data will be backed up on the university's cloud and Pretty Manyimo will be responsible for backing up the data.

How will you manage access and security?

Only the principal investigator, the two named supervisors and an approved University of Warwick administrator will be able to access the data.

The researcher will ensure safe transfer from the research field as they will used a password protected

laptop, which will be securely stored in the car boot on transit.

Selection and Preservation

Which data are of long-term value and should be retained, shared, and/or preserved?

Demographic data and consent forms will be retained up to three months after the publication of the study.
Research data will be retained up to ten years after the study publication, reviewed, and then securely deleted.

What is the long-term preservation plan for the dataset?

Data will be held in the University of Warwick repository and will be archived by the responsible data administrator.

Data Sharing

How will you share the data?

Data will not be shared outside the University of Warwick and Marie Curie.

Are any restrictions on data sharing required?

The University of Warwick and Marie Curie hold IPR and have data honourship rights

Responsibilities and Resources

Who will be responsible for data management?

The named University of Warwick is the research sponsor. The university has put in place activities to ensure that Pretty conducts the research in a responsible manner, and have provided training and policy guidance. The supervisors will be responsible for Pretty Manyimo's mentoring.
Pretty Manyimo has received training to conduct this research, but may need additional training if need arises. The training includes Good Clinical Practice to conduct the research. She will be responsible for:

- implementing the DMP and will ensure it is reviewed and revised.

- all data management activity ie data capture, data storage and data sharing
- ensuring they respect relevant policies.

The University of Warwick will be the data controller and will be responsible for:

- ensuring relevant policies will be respected.
- data archiving.

The Warwick Medical School administrator and the supervisors will have access to the data. In the event that Pretty Manyimo is no longer at the University of Warwick, the supervisor or administrator will be responsible for deletion of data 10 years after the study has been completed.

What resources will you require to deliver your plan?

Pretty Manyimo is a PhD student and will continue identifying any required training and attend any training provided.

The supervisors Dr John MacArtney and Professor Celia Lury will supervise and advise throughout the project.

I will need access and training on using the NVIVO software.