



PATIENT AND CAREGIVER PARTICIPANT INFORMATION SHEET

What can be learned from the experiences of those receiving and giving emotional support by video call to adults with life-shortening illnesses in palliative care services?

The researcher

My name is Michèle Wood, and I am conducting this research as part of my PhD in Palliative Care at Lancaster University, Lancaster, United Kingdom.

What is the study about?

I'm looking at how, why and in what circumstances palliative care organisations use video calls to offer emotional support to patients and their friends or relatives. The purpose of this study is to identify factors that will help improve the care of people living with life-shortening illnesses.

Organisations are now using technology such as Zoom, FaceTime, Google Meet or Microsoft Teams to make video calls. Emotional support offered by video call in some settings is provided by arts therapists, counsellors, psychotherapists, psychologists, chaplains, social workers or any other healthcare practitioners trained to give emotional support. My research will look at the experiences of patients and informal caregivers who are receiving this help. The study also looks at the experiences of the staff and volunteers (healthcare practitioners, managers, technical, administrative staff) providing this help.

Why have I been asked to take part?

We want to listen to people with direct experience of being offered emotional support through video calls, and from the staff and volunteers who deliver these.

Who can take part?

Patients, informal carers, family members, or bereaved caregivers who are using or have used palliative care services, which included video support, and the staff/volunteers whose role is to provide indirectly or directly these video calls can take part in this study.

Do I have to take part?

No. It's completely up to you to decide whether or not you take part.

How can I find out more about the study?

If you would like to take part, please get in touch to arrange a time for us to speak about what the study involves. My contact details are at the bottom of this leaflet. You can also ask a member of staff to let me know you are interested.

What will I be asked to do if I take part?

There are three ways to take part, although not everyone will need to do all of them. You will be asked to confirm you have received and understood the study information and are happy to take part by completing a written consent before starting each of the following:

1. Observations

I am interested to see what is involved in setting up for a video call, how people manage technology, equipment, space, and what steps are taken to make the experience worthwhile. I will watch the typical activities of video calling and make notes to help me remember my observations. Ideally observations will happen in the place where you usually have your video calls, or we can find another location if that would be easier. There will be an opportunity to talk about the observation afterwards.

2. Collaging

Everyone will be asked if they want to do a collage as a way of making a picture about what it feels like being supported by video call. This involves making your own picture from pre-cut magazine images, photos, patterns, or words. All items for this will be provided. You can do this activity in a comfortable space in the care setting or at home. There are no right or wrong ways to do collaging and no special skills needed beyond selecting and sticking collage pieces. Collaging can be a more effective way to share ideas than talking. Once your collage picture is finished you will need to give it a title and write this on a separate sheet of paper, adding, if you wish, any comments about what you have made. These will be posted to me in the envelope provided and used as research data. You don't need to send me your collage picture, but you can if you wish. If so, your collage may be photographed and used in the research report, but you will not be able to be identified from it (your name will not be included).

3. Interviews

This involves individual meetings with the researcher who will ask a few questions about participants' experiences and how they see video calls being used for the emotional support of other patients and families in the future.

If I agree to be interviewed what will happen?

We will arrange a suitable time and place to meet. This can be in person or online. If you have made a collage, you can show it to me as a way of explaining your experiences further. I can take a photograph of your collage to include in the study if you wish. As you talk, I will make a map of key words that seem important to you. This is called a 'concept map' and you will be able to add to or change it during the interview. The interview will be audiotaped and listened to afterwards by the research team (me and my supervisors) to identify information relevant to the study's overall aims. We will write this out (transcribed and stored electronically), and then the recording will be deleted.

Will people know that I have taken part?

All names will be removed and replaced with aliases that have no connection with actual participants or organisations to ensure they cannot be identified.

Are you looking at anything else?

Yes, to understand how your care organisation works I will look at publicly available documents such as: Information leaflets; the organisation website; policies; Standard operation protocols; service user feedback. I will not be looking at individual participants' personal documents or records.

What procedures for security of information will be followed?

This study complies with EU General Data Protection Regulation (GDPR) and the UK's Data Protection Act 2018. During all stages of the research process all names and other identifying features will be replaced with codes (e.g., Participant 1 Site A) and saved as encrypted digital files only accessible to the researcher. These will be securely stored on a password-protected computer and backed up on the Lancaster University approved secure cloud storage and kept for no longer than 10 years after the research study has finished. If a professional transcription service is used, they will sign a confidentiality agreement.

Key points to note are:

- Audio recordings will be destroyed and/or deleted once the thesis has been examined and reports submitted for publication.
- Hard copies of all participants' collage title and comments sheets will be kept securely in a locked metal cabinet for ten years. At the end of this period, they will be destroyed.
- The files on the computer will be encrypted (that is no-one other than the researcher will be able to access them) and the computer itself password protected.
- At the end of the study, all electronic documents will be archived in a secure repository at Lancaster University and kept for ten years. At the end of this period, they will be destroyed.
- The typed version of your interview will be made anonymous by removing any identifying information including your name. Anonymised direct quotations from your interview may be used in the reports or publications from the study, so your name will not be attached to them.
- All your personal data will be confidential and will be kept separately from your interview responses.

There are some **limits to confidentiality**: if what is said in the interview makes me think that you, or someone else, is at significant risk of harm, I will have to break confidentiality and speak to a member of staff about this. If possible, I will tell you if I have to do this.

What will happen to the results?

The results will be summarised and reported in a PhD thesis and may be submitted for publication as articles for academic, professional, and general public audiences. No one who has taken part will be able to be identified, so no names will be included. All those who took part will be asked if they would like a summary of the findings in which case, they will give their contact details to the researcher to be securely stored on the Lancaster University

approved secure cloud storage in a password protected file, and only opened once the study is completed. Participating organisations will also be sent a summary.

Are there any risks?

There are no risks anticipated with participating in this study. However, talking about emotional support may cause anxiety and distress for some people, so if you experience any anxiety and/or distress at the time or afterwards you are encouraged to let me know and to contact any of the resources listed at the end of this sheet.

Are there any benefits to taking part?

Although you may find taking part interesting, there is no payment or other direct benefits in taking part.

Who has reviewed the project?

The sponsor for this project is Lancaster University and the study has been reviewed and approved by the NHS Research Ethics Committee Reference: 22/WM/0113

Where can I obtain further information about the study if I need it?

If you have any questions about the study, email me, Michèle Wood:

m.wood8@lancaster.ac.uk or

my supervisor Professor Catherine Walshe: c.walshe@lancaster.ac.uk

or scan the QR code at the end of this document

Complaints

If you wish to make a complaint or raise concerns about any aspect of this study and do not want to speak to the researcher, you can contact:

Professor Fiona Lobban
Director of Research
Department of Health Research
Lancaster University, Lancaster LA1 4YD

If you wish to speak to someone outside of the PhD Palliative Care Programme, you may also contact:

Laura Machin, FHM Research Ethics Committee Chair

E-mail: l.machin@lancaster.ac.uk

Tel: +44 1524 594973

Faculty of Health and Medicine

(Lancaster Medical School)

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LA1 4YG

RESOURCES IN THE EVENT OF DISTRESS

Should you feel distressed either as a result of taking part, or in the future, the following resources may be of assistance.

Local resources

Your usual palliative care staff team (consultant, nurse or psychosocial team members)

Your local GP

For local mental health support put your postcode into the NHS website

<https://www.nhs.uk/service-search/other-services/Mental-health-support/LocationSearch/330>

Or for counselling put your postcode into <https://www.psychologytoday.com/gb>

National resources

<https://www.mariecurie.org.uk/help/support>

<https://www.macmillan.org.uk/cancer-information-and-support/treatment/if-you-have-an-advanced-cancer/end-of-life/relationships-and-other-matters>

<https://www.carersuk.org/>

<https://www.baatn.org.uk/>

<https://www.pcpld.org/links-and-resources/>

<https://www.bacp.co.uk/search/Therapists?q=>

Terms used in this study

Palliative care aims to relieve symptoms and suffering in people living with life-shortening illnesses. It is usually provided by a range of healthcare professionals working together.

Emotional support aims to address distressing thoughts and feelings that diminish a person's quality of life. A variety of social, psychological and arts techniques and approaches can be used for this.

Collaging is an artistic technique of putting together a new picture from pre-cut magazine images, photos, patterns or words.

Concept mapping is a research technique where important words are written in the form of a spider diagram or mind map.

Video calling is where people in different locations use digital devices with cameras and screens to connect at the same time.

Thesis is the written report about the research project and its findings which will be examined for the PhD award.

Lancaster University will be the data controller for any personal information collected as part of this study. Under the GDPR you have certain rights when personal data is collected about you. You have the right to access any personal data held about you, to object to the processing of your personal information, to rectify personal data if it is inaccurate, the right to have data about you erased and, depending on the circumstances, the right to data portability. Please be aware that many of these rights are not absolute and only

apply in certain circumstances. If you would like to know more about your rights in relation to your personal data, please speak to the researcher on your particular study. For further information about how Lancaster University processes personal data for research purposes and your data rights please visit our webpage: www.lancaster.ac.uk/research/data-protection



Scan QR code for more about the study

Thank you for taking the time to read this information sheet