Participant Information Sheet - Amputees

An exploration of how religion and culture shape perceptions, experiences and practices of the disposal of amputated limbs in the UK

Please read this information carefully. Please ask if anything is not clear, or if you would like any more information.

What is the purpose of the research?

This research is for my PhD study which explores how religion and culture shape patients' experiences of the disposal of amputated limbs in the UK.

Religion and spirituality provide a sense of purpose and meaning to life. Religion and spirituality also provide coping mechanism for adverse life events such as loss and illness. There is a growing appreciation of the benefits of religion and spirituality in healthcare and the need to provide holistic care and incorporate religion and spirituality into patient's medical care and treatment plans and options.

Little is known about the influence culture and religion might have on the disposal of amputated limbs. Patients might be curious about what happens to their amputated limbs and whether they will be treated with dignity and according to their cultural and religious beliefs. Knowing how amputated limbs will be disposed can be a crucial part of the adjustment process of amputation for some patients and not addressing this may make the healing process and the realisation of the new self harder. There is a need to generate insights on patients spirituality and how healthcare professionals can facilitate integration of patients spirituality into their care. This study will provide understanding of how religion, spirituality and culture can shape patients' experiences in their amputation care.

Why have I been chosen?

You have been invited to participate because you have experience of amputation, live in the UK and are 18 years and above.

Spirituality means many different things to people, nevertheless *"You don't need to be part of a religious group to fall ill and then ask yourself, wow who am I, what's my life all about, is there purpose in suffering, where have I come from, where am I going, what gives me meaning and value, what makes my life meaningful, important, is it all for nothing?"*

In light of the above explanation, this study seeks to interview all amputees - those who identify with organised religion and those who do not.

What does taking part involve?

Taking part involves being interviewed about your spirituality, religion and culture and how they may shape perceptions, experiences and practices of the disposal of amputated limbs and amputation in general. The interview questions will ask about your own spirituality, religious beliefs, and practices and how they apply to the experience of amputation. The interview will also cover your spiritual and religious beliefs and practices about the body and disposal of body parts. The interview should take approximately an hour and can either be conducted by telephone or video on Microsoft teams or face to face in a public location. You will receive a £10 high street gift voucher as a 'thank you' for participating in the interview.

What about confidentiality?

If you agree to take part in an interview, I will ask if I can digitally record the interview so that I can accurately capture the information you provide. Anything that could be personal to you, such as your name and location, will be changed to protect your identity when the interview is transcribed. Only my supervisors will have access to the transcript and recording, and the information obtained will be used only for the purpose of this research. Files will be saved under a code, such as P1, P2 etc so that no identifying information is saved in the file names. All data will be stored on Figshare – a secure cloud storage site. If I use a transcription service, I will handle research data securely and confidentially, in compliance with the law and with DMU's institutional requirements for the handling of personal data. All information will be stored in accordance with the General Data Protection Regulation for ten years after the end of the project which is April 2035 after which it will be deleted.

Your participation in the study will be confidential, unless anything that is raised gives the researcher cause for concern about serious risk or harm to yourself or to others. In this case, the researcher would follow DMU's safeguarding policies and procedures. All data will be processed in accordance with DMU's privacy and data protection policy which can be found here: https://www.dmu.ac.uk/policies/data-protection/data-protection.aspx

What will happen to my contribution?

Your interview information will be considered and analysed alongside other data generated in the research and presented (anonymously) in the final thesis in partial fulfilment of my PhD award. I may also use the data to publish journal articles and to present at conferences. All information used in publications will be anonymous.

Can I withdraw from the research?

Taking part in the interview is voluntary. You can withdraw from the research if you wish and I will not include your views in the findings. If you wish to withdraw from the project, please contact me via the contact details below. Due to the method that would be used for analysis requiring data to be analysed soon after interview, you will have up to 2 days after the interview to withdraw your participation. Participants can also stop the interview at anytime and their information will be deleted.

What happens now?

If you are willing to take part, contact the researcher directly (contact details given in participant information sheet) who will arrange a date/time for the interview to take place.

Who is conducting and funding the research?

The research is being conducted by Matilda Hanjari (PhD student), Supervised by Dr. Esmée Hanna, Institute for Applied Health Research at De Montfort University, Leicester. This research is funded by a De Montfort University studentship.

Can I find out the outcome?

The researcher will write a summary of the findings from the study. If you would like a copy, you can contact me about this in the future- I anticipate these findings being available in summer 2025 shortly after I submit my thesis.

Who has reviewed the study?

The research has been reviewed and approved through De Montfort University Research Ethics procedures.

What happens if I have a problem with the research?

If you have a concern about any aspect of this research you should ask to speak to me, Matilda Hanjari (my contact details given below) and I will do my best to answer your questions. You could also contact my supervisor Dr. Esmée Hanna (Email: esmee.hanna@dmu.ac.uk). If you remain unhappy and wish to speak to someone independent from the study, you can do this through the Health and Life Sciences Faculty Research Ethics Committee: hlsfro@dmu.ac.uk.

If you have any questions about the research, please contact the researcher who is leading this study, the contact details are below for you.

Researchers contact details:

Matilda Hanjari, Leicester School of Allied Health Sciences, De Montfort University, The Gateway, Leicester LE1 9BH. Email: P2670697@my365.dmu.ac.uk

Sources of support

- Your GP
- Other healthcare professionals that support you.
- Local counselling service (This may need a GP referral)
- Amputation organisations such as the Limbless Association and Sian Green Foundation Contact@siangreenfoundation.com
- Amputee support groups https://steelbone.co.uk/amputee-support-groups-uk-and-global/. The national websites can also help in finding local branches.

Key phone numbers:

- The Limbless Association - 0800 644 0185. Available Monday to Friday, 9am until 5pm (Excluding Bank Holidays)
- Amputation Foundation - 01744 808 850.
- Samaritans – 116 123