Information Letter for Participation in a Research Study

Title Identifying Families' Needs during Palliative Care Post-stroke: A Qualitative Study

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Co-Investigators

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Granting Agency: Heart and Stroke Foundation of Canada

Introduction

You are being asked to take part in a research study. This document describes the research study that you could take part in if you agree. Please read this explanation about the study and its risks and benefits before you decide if you would like to take part. You should take as much time as you need to make your decision. You should ask the study staff to explain anything that you do not understand and make sure that all of your questions have been answered before agreeing to participate (contact information can be found above). The following information describes the purpose, procedures, benefits, discomforts, risks and precautions associated with this study. Participation in this study is voluntary. Upon contact, if you agree to set up a telephone interview, you are allowing us to use the data you provide for research purposes.

Purpose

You are being asked to participate in this study because you are a family member or friend of a person who has suffered a stroke and has passed away. The purpose of this study is to explore families' experiences during **palliative care** (specialized care for someone with a serious illness), **end-of-life care** (care for someone with a terminal illness or condition), and **bereavement** (a period of grieving after a loved one dies). We aim to understand your experiences and needs as you experienced palliative care, end-of-life care and bereavement. By understanding your experiences and those of others like

you, we will develop programs to assist future families as their loved one receives palliative care.

Procedure
You are being asked to participate in a telephone interview to discuss your experiences with palliative care, end-of-life care and bereavement. Your participation in this study is voluntary. You can choose not to participate, refuse to answer a question, or withdraw at any time without penalty or loss of benefits to you. The telephone interview should last approximately 60 minutes and will be audio-recorded. If you choose to take part in this telephone discussion, please provide us with your name and contact information in the postage-paid envelope provided. A member of the study team will be in contact with you to set up an interview.

Eligibility (Who can participate in the study?):
If you have provided care or assistance to a family member or friend who has passed away after a stroke at least 3 months ago, we are interested in hearing about your experience. Family members should be 18 years of age or over and speak English. We would like to speak with family members who were actively involved in the process of end-of-life care and who were involved in providing care and/or support to the stroke patient. Participation in this study is voluntary.

Researchers (Who will be conducting the research?):
During the study, if you have any questions you can contact the research assistant, Kristina Kokorelias at 416-978-5694 or k.kokorelias@mail.utoronto.ca.

Risks
Some people find that thinking or talking about their situation makes them upset or sad. The interviewer will be able to support you if you become distressed, and if you wish you will be able to take a break, or stop answering the questionnaires or the interview at any point. At the end of this letter, there is a list of bereavement support services available in the community.

Benefits
It is very important for researchers and healthcare professionals to know the views of family members of stroke patients such as yourself so that we can plan the services provided to them based on their needs. We hope that you may find it helpful to have an opportunity to talk about your experiences.

Confidentiality
If you agree to join this study, the study doctor and her study team will ask you to provide some personal information and share your experiences in an audio-recorded telephone interview. The telephone interview will be transcribed by a professional transcriber.

The information that is collected for the study will be kept in a locked and secure area by the study doctor for 5 years. Only the study team or the people or groups listed below will be allowed to look at your records.

The research study you are participating in may be reviewed for quality assurance to make sure that the required laws and guidelines are followed. If chosen, (a) representative(s) of the University of Toronto Human Research Ethics Program (HREP) may access study-related data and/or consent materials as part of the review. All information accessed by the HREP will be upheld to the same level of confidentiality that has been stated by the research team.

All information collected during this study, including your personal health information, will be kept confidential and will not be shared with anyone outside the study unless required by law. You will not be named in any reports, publications, or presentations that may come from this study.

If you decide to leave the study, the information about you that was collected before you left the study will still be used unless you request for it to be withdrawn. No new information will be collected without your permission.

At the completion of data analysis and publication, a summary of the results will be published on Dr. Cameron's website www.familyresearchgroup.weebly.com.

Participation
Your participation in this study is voluntary. You can choose not to participate or refuse to answer a question, or withdraw at any time without penalty or loss of benefits to you. Once you mail back the enclosed contact form, the study coordinator will be in contact with you to answer any questions, and set up an interview time.

Compensation
There are no costs associated with participation in this study. The study investigator is not being compensated for conducting this study. Upon completion of the interview, you will receive a $25 visa gift card via mail.

Liability
In no way does this information letter waive your legal rights nor does it relieve the investigators, sponsors or involved institutions from their legal and professional responsibilities.

Questions
If you have any questions about the study, please call the study assistant, Kristina Kokorelias at 416-978-5694 or the principal investigator, Jill Cameron at 416-978-2041.

If you have any questions about your rights as a research participant or have concerns about this study, call Rachel Zand, director of Human Research Ethics at the UNIVERSITY OF TORONTO at 416-946-3389.

The UNIVERSITY OF TORONTO ETHICS BOARD is a group of people who oversee the ethical conduct of research studies. These people are not part of the study team. Everything that you discuss will be kept confidential.

Consent

This information letter is to be kept for your records. You have been given the opportunity to ask the study investigators any questions you had about the study, and your questions and/or concerns have been answered to your satisfaction. If you decide at any time during the study to withdraw your consent, you may do so by contacting a member of the study team. In no way does this waive your legal rights nor release the investigators, sponsors or involved institutions from their legal and professional responsibilities. Your continued participation should be as informed as your initial consent so that you are free to ask for clarification or new information throughout your participation in the study. We will also ask you to provide verbal consent before we begin the interview.