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Research Project Description and Researcher Contact Information

Title of Research Project: Families' Experiences Living with ABI: A Narrative Inquiry Study

Research Purpose

I am inviting you to consider taking part in this study.

As a researcher I want to learn from both individuals and family members together as a group about your experiences living with ABI - your perspectives and loss experiences.

Who Can Participate?

I would like to recruit five –six families that live in different regions of Manitoba. For this study family will consist of a **maximum** of 5 family participants, per family unit, including the member with the ABI; or-a **minimum** of 3 participants for each family group, including the member with the brain injury. You will determine which of your family members participate. Family participants can include: persons who support, share a history and a future, and are committed and caring towards each other. Participants can include friends as well as biological and legal family member participants. Neither the individual member with the ABI nor the other family members need to be residing within the same household. All participants need to be over the age of 18, able to speak and read English, and willing to participate in a family group interview. For the individual with the ABI, the individual needs to be living in the community, a minimum of two years after the initial brain injury event, and medically stable. Family will consist of at least the individual member with the ABI and up to a maximum of four other self-defined family members.

What Would I Have To Do If I Agree To Participate?

Families will participate in two face to face interviews. The first interview will be approximately two-three hours in length. A brief break during this interview can occur if you need one. If you choose to participate in the 2nd interview it will be approximately 1hour long. You will be offered a choice on the location for the interviews. The interviews will be digitally audio-recorded and transcribed through a designated transcriptionist.

During the beginning of the first interview I will collect demographic information about your family. I will ask questions concerning the age, occupation, education of each family member, as well as ABI diagnosis, post injury time and family constellation information. I will also be collecting information on your families' contact with larger systems and how you communicate with each other. Following the gathering of this information you will then be asked to think



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about your life experiences with ABI as three life stage chapters in a book about your family. The first chapter is about your family life before the ABI event, the second chapter is now – living with ABI, and chapter three concerns your future family life. I will then be asking you to tell me about different family events or situations that you experienced during each of these chapters.

The second interview will be scheduled to take place three-four weeks following the first interview. The purpose of the less structured second interview is to follow up with your families' reflections from the first interview, clarify uncertainties and any additional perspectives and experiences you wish to relate. To help you to remember what you said in the first interview facilitate I will review the transcript and provide you with points made in their first interview for you to review in advance. The second interview, held in the same location as the first interview, will also be audio recorded and transcribed.

Is Participation Voluntary?

Your participation is a choice, your consent is voluntary and you may choose to withdraw from the study at any time with no repercussions. In recognition for your time and to offset some transportation costs, each family member will be offered \$25 in cash for participating.

If you are interested in participating in the interview component of this doctoral research project please contact:

Jane Karpa (the principal researcher) at email: umkarpaj@myumanitoba.ca and or
Phone: 204.896.0456.

The Education and Nursing Research Ethics Board has approved this research. If you have any concerns or complaints about this project you may contact the above-named person or Dr. Wanda Chernomas (204.474.6819; Wanda.Chernomas@umanitoba.ca) or the Human Ethics Coordinator (HEC) at the University of Manitoba (474-7122).