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RESEARCH PARTICIPANT INFORMATION AND CONSENT FORM Individual Interview

Title of Study: Live-in Caregivers Perspectives on the Provision of Homecare Services in Manitoba

Principal Investigator: Kaitlyn Kuryk, Department of Sociology and Criminology,
301C Isbister Building, 204-250-3706, obedzink@myumanitoba.ca

Co-Investigator: Dr. Christopher Fries (supervisor), Department of Sociology and Criminology
317 Isbister Building, 204-474-7871, christopher.fries@umanitoba.ca

This consent form, a copy of which will be left with you for your records and reference, is only part of the process of informed consent. It should give you the basic idea of what the research is about and what your participation will involve. If you would like more detail about something mentioned here, or information not included here, you should feel free to ask. Please take the time to read this carefully and to understand any accompanying information.

Purpose of this Study

This research study is being conducted to better understand the experiences of live-in family caregivers in Manitoba. The Principle Investigator, Kaitlyn Kuryk, is studying home care and the impact that it has on live-in caregivers and the home in which they reside. As part of her Ph.D. dissertation research, she is interested in learning about your experiences of being a live-in caregiver, and how this may have shaped you, and how you think about life, family, and home. She is also interested in exploring the kinds of physical changes or adaptations that have been made to your home since starting with the home care program. Her personal experience with home care led to her sociological interest in these services, and she is interested in understanding the experience of others, and potentially making positive changes in the home care system as a result of the study.

Participants Selection

You are being asked to participate in this study because, as a caregiver who lives with a recipient of home care, you have a unique perspective of home care services. Academic studies often research home care recipients, and the perspectives of caregivers are not always included. Thus, it is important to understand your perspective, particularly, how home care services may affect the home in which you currently live.

I hope to speak with about 20 live-in caregiver participants

Study procedures

- The method of data collection for this study will be individual interviews and a brief tour of your home.

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- Participation in the study will involve one interview lasting approximately 1.5-2 hours, followed by a brief tour of your home (5 to 10 minutes).
- The Principle Investigator of this study, Kaitlyn Kuryk, will be conducting the interview. She will be the only researcher entering your home.
- You will be asked some questions relating to your experience with home care services in Manitoba. These questions will help us to better understand your experience of caregiving, and how home care services have impacted your home.
- With your permission, the sessions will be audio-recorded and the audio-records will be transcribed by Kaitlyn Kuryk to ensure accurate reporting of the information that you provide.
- Your name will not be asked or revealed during the interview while the recording device is on. However, should your name, or your loved one's name be revealed, Kaitlyn Kuryk will remove it from the transcription.
- Kaitlyn Kuryk will also take handwritten field notes during the interview in which she will record her general impressions of the interview and how it went. No identifying information will be included in these field notes (anonymized).
- Following the completion of the interview, Kaitlyn Kuryk will ask for a tour of your home, particularly where care is provided to your loved one, and where you take time for yourself away from your caregiving responsibilities. Of course, it is up to you whether you would like to show me your home and if so, which parts. Only photos of objects in the home space (not people) will be taken, and permission will be asked before each photo is taken. You will get a chance to review the photos at the end of the interview. During this tour, Kaitlyn Kuryk will take additional field notes, and may, with your permission, take pictures. No identifying information will be included in these pictures. Consent to have pictures taken will be provided below.
- Participants will be given the option of receiving a non-technical, lay language summary of project results either by email or regular postal mail, as preferred (they will indicate this on the informed consent form). This summary would include a thematic presentation of general findings from the constellation subproject as well as the other components of the project. You will receive the summary by 05/23.

Risks and Discomforts

There are very few risks anticipated for participants. However, you may find talking about your caregiving experience to be upsetting or emotional. You do not have to answer any questions that make you feel uncomfortable or that you find upsetting. Should you need any additional help or support Kaitlyn Kuryk will provide you with a list of caregiver supports and help you to find other counseling help.

If a home care recipient is living at home and Kuryk believes that they are in danger as a result of abuse or neglect, disclosure of the information collected would be permitted under The Personal Health Information Act and will be reported to the police. Under such circumstances, participants will be notified that police will be informed if abuse is suspected.

Benefits

Being an interview participant may not help you directly, but the information gained through your experiences may help other family caregivers in the future. For example, other family caregivers may resonate with your experiences. Additionally, the experiences that you share may also help to inform policy work that benefits caregivers in Manitoba.

Costs

There is no cost to you to attend the individual interview.

Payment for participation

You will be given a \$25 grocery store gift card for agreeing to participate in this study. You will receive the gift card prior to the start of the interview and you may keep this gift, even if you decide to leave the study

Confidentiality

I will do everything possible to keep your personal information confidential. Your name will not be used at all in the study records. A list of names and addresses of participants will be kept in a secure file so we can send you a summary of the results of the study. If the results of this study are presented in a meeting, or published, nobody will be able to tell that you were in the study. Please note that although you will not be identified as the speaker, your words may be used to highlight a specific point. Pictures taken in your home may also be used, thus there is a slight risk of identification. However, to minimize this risk, only photos of objects will be taken (no people) and you will have a chance to review each picture. The collection and access to personal information will be in compliance with provincial and federal privacy legislation.

Audio recordings of the interview will be transcribed and used as data analysis to prepare a Ph.D. dissertation, and other academic works such as journal articles, books, book chapters, and reports among others. The audiotapes and typed notes will be kept for 6 years (until approximately 08/28) on Kaitlyn Kuryk's secure University of Manitoba OneDrive account. Only the Principal Investigator and Supervisor will have access to them and know your name. Interviews will be audio-recorded on a digital recorder and transferred immediately after the interview onto the interviewer's password-protected personal computer and saved as an encrypted file labeled with a code name/file number in a secure computer program. It will be deleted immediately from the audio recorder.. They will remain on OneDrive until 08/28, at which time they will be deleted. Only the interviewer (PI, Kaitlyn Kuryk) and supervisor (Dr. Fries) will have access to these files. In a word document, the interviewer will also record field notes following each interview in which they record their general impressions of the interview and how it went.

All paper records will be kept in a locked secure area at the University of Manitoba and only those persons identified will have access to these records. If any of your research records need to be copied to any of the above, your name and all identifying information will be removed. No information revealing any personal information such as your name, address or telephone number will leave the password-protected laptop of Kaitlyn Kuryk.

Voluntary Participation/Withdrawal from the Study

Your decision to take part in this study is voluntary. You may refuse to participate or you may withdraw from the study at any time. You may choose to withdraw from the study at any point until data is disseminated (approx. 05/23).

Your decision not to participate or to withdraw from the study will not affect your loved one's home care services.

Dissemination

Study results will be published in Kaitlyn Kuryk's Ph.D. dissertation. They may also be published in academic journals, books, book chapters, reports, and conference presentations.

Questions

If any questions come up during or after the study contact the principal investigator and/or supervisor: Kaitlyn Kuryk at 204-250-3706 or Dr. Christopher Fries at 204-474-7871.

For questions about your rights as a research participant, you may contact The University of Manitoba, Fort Gary Campus Research Ethics Board Office at (204) 474-7122.

Your signature on this form indicates that you have understood to your satisfaction the information regarding participation in the research project and agree to participate as a subject. In no way does this waive your legal rights nor release the researchers, sponsors, or involved institutions from their legal and professional responsibilities. You are free to withdraw from the study at any time, and /or refrain from answering any questions you prefer to omit, without prejudice or consequence. Your continued participation should be as informed as your initial consent, so you should feel free to ask for clarification or new information throughout your participation. The University of Manitoba may look at your research records to see that the research is being done in a safe and proper way. This research has been approved by the Research Ethics Board at the University of Manitoba, Fort Garry campus. If you have any concerns or complaints about this project you may contact any of the above-named persons or the Human Ethics Officer at 204-474-7122 or HumanEthics@umanitoba.ca. A copy of this consent form has been given to you to keep for your records and reference.

Consent Signatures:

Please review each of the following **carefully** with the interviewer. Check the corresponding box only if you agree to each item.

1. I have read all 5 pages of the consent form.
() Yes () No
2. I have had a chance to ask questions and have received satisfactory answers to all of my questions.
() Yes () No
3. I understand that by signing this consent form I have not waived any of my legal rights as a participant in this study.
() Yes () No
4. I understand that my records, which may include identifying information, may be reviewed by the research staff working with the Principal Investigator.
() Yes () No
5. I understand that I may withdraw from the study at any time and my data may be withdrawn prior to publication.
() Yes () No
6. I understand I will be provided with a copy of the consent form for my records.
() Yes () No
7. I consent to have the interview audio recorded.
() Yes () No
8. I consent to have photos taken in my home.

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Yes No

9. I consent to have photos used in publications.
 Yes No

10. Do you wish to receive a general summary of the findings (by approx. May 2023)?

11. Yes No

If YES: Email or Surface Mail Address, as preferred to receive these findings:

12. I agree to participate in the study.

Yes No

Participant signature _____

Date _____
(day/month/year)

Participant printed name: _____

Researcher's Signature _____

Date _____
(day/month/year)

If you have any questions or concerns, contact Kaitlyn Kuryk, the lead for this project (see contact information in the header of this form), or Dr. Christopher Fries, Supervisor (204-474-7871 or Christopher.fries@umanitoba.ca). This research has been approved by the Psychology-Sociology Research Ethics Board at the University of Manitoba, HE2022-0061. If you have any concerns or complaints about this project you may contact any of the above-named persons