INFORMATION AND CONSENT FORM

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This study was approved by Ryerson University's Research Ethics Board (the filed REB number for this study is 2018-456). Ryerson University's REB can be contacted at 416-979-5000 ext. 4841 or zakiya.atcha@ryerson.ca.

Background

We define a carer as "a person who takes on an unpaid caring role for someone who needs help because of a physical or cognitive condition, an injury or a chronic life-limiting illness." In 2012, about a quarter of Canadians over the age of 15 participated in unpaid work through caring for a friend or loved one living with chronic injury or illness. This suggests that at least 1 in 4 Canadians may have experienced, or are currently facing significant emotional, mental, and/or physical health challenges related to insufficient supports and limited resources.

Although Canada's more recent efforts include supporting carers as a whole, such as a national strategy to address dementia (Bill C-233; Parliament of Canada, 2017), there is no mention of strategies specifically meant to support young carers (unpaid carers who are under 25 years old). There are more than 185,000 young carers in Canada (aged 15-24) who care for a loved one through 15 or more hours of unpaid caregiving.

In this study, we are defining young carers as people under the age of 25. According to the Canadian census data from 1996–2006, the number of young carers, aged between 15-24, increased by 13.5%. Currently, only three programs provide targeted support for Canadian young carers (two in Ontario and one in British Columbia). Findings from our previous scoping review and qualitative study exploring the experiences of young carers indicate there is a need for services and resources to meet the unique needs of this population.

Inclusion and Exclusion Criteria

Participants must be at least 18 years of age and either a licensed practical nurse, registered nurse, or nurse specialist (i.e., nurse practitioner, clinical nurse specialist, nursing educator, advanced practice nurse).

Purpose and Significance of this Study

Given the existing limitations in resources and services for young carers in Canada, we decided to undertake this study to see how prepared and knowledgeable nurses are in providing support to the ever-growing population of young caregivers.

Nurses play a crucial role in identifying young carers in the community and in health care settings. In doing so, nurses can assess the needs of young carers and offer support and resources. However, nurses' ability to identify young carers and their ability to provide support is dependent on their knowledge and resources they have to offer. To our knowledge, no Canadian study has looked at nurses' knowledge or preparedness to support young carers. Therefore, the purpose of this study is to explore nurses' perceptions of their preparedness to care for this population. The study will address the following research questions:

1. *What is the current knowledge that nurses have of young carers in Canada?*
2. *What skills and resources do nurses have to support young carers in Canada*
3. *What do nurses need to better provide support for young carers in Canada?*

What Participation Involves

If you agree to participate in this study, you will be asked to complete an online survey asking about your experiences working with young carers and your current knowledge related to caring for this population. You will also be asked some demographic questions about your role, practice setting, education, years of practice, and questions related to your knowledge about young carers and your needs in supporting young carers. It is highly recommended that you look over the survey by clicking on the direct link within our recruitment email. The survey will take 15-20 minutes to complete. We intend to recruit 1000 people for this study.

How Your Information and Data will be kept Anonymous and Stored Securely

The survey will be conducted using Google Forms. Google Forms encrypts all data that you provide and is securely stored on Google servers. For more information about Google's servers, please visit https://www.google.com/about/datacenters/inside/data-security/index.html

To keep your identity completely anonymous, we will ask you to develop a unique participant ID consisting of the *first 3 letters of your first name* and *the last 3 letters of your postal code* (i.e., Arthur M5G 3Y8 = ART3Y8). If you are unable to fully complete the survey for any reason (i.e., computer shuts down, browser closes), all partial data will not be saved and will automatically be deleted. Your information and data will be stored on an electronic password-protected Excel spreadsheet. This spreadsheet will be stored on an encrypted USB key that will be kept in a locked filing cabinet in Dr. Newman's office at the university. Study findings will be reported using aggregate data, no identifying information will be presented in any publications or presentations. The data we obtain for this study will be kept for 5 years and then deleted from all devices where it was stored.

How Your Data is Going to Be Used

The data obtain from this study will only be reported in aggregate form in journal articles and conferences.

What to do if you want to Withdraw from this Study

Your participation in this study is VOLUNTARY and should you choose not to participate, this will not influence future relations with the researchers conducting this study, Ryerson University, or your membership in a professional association/organization. You may withdraw from this study before analysis has begun in June of 2019. If you wish to withdraw from this study, email Dr. Kristine Newman at kristine.newman@ryerson.ca and provide us with your participant ID consisting of the first 3 letters of your first name and the last 3 letters of your postal code (i.e., Arthur M5G 3Y8 = ART3Y8).

Benefits and Risks of Participation

Through participating in this survey, it is anticipated that you will be able to identify your current knowledge and skills related to supporting young carers. Your participation will provide valuable information about the current nature of nurses' ability to support young caregivers in Canada. The data from this study will help to develop knowledge on how the healthcare system can be strengthened to better support young carers and could inform recommendations for practice and policy.

Although it is unlikely, you may experience some emotional discomfort that could be caused by the realization of the limitations of knowledge or resources you can access to support young carers. At the end of the survey, a link is provided to strengthen your knowledge and preparedness to support young caregivers.

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If you have any questions or concerns, please contact Dr. Kristine Newman at kristine.newman@ryerson.ca