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Dementia Education: What are the Needs of Post-Secondary Students in London, Ontario?

Tri Le

Fanshawe College of Applied Arts and Technology, t_le5@fanshaweonline.ca

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Dementia Education: What are the Needs of Post-Secondary Students in London, Ontario?

Tri Le

Fanshawe College

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Abstract

Dementia is a chronic and progressive syndrome characterized by the disturbance of multiple brain functions. As of 2008, an estimated 500,000 Canadians will have a dementia diagnosis and is predicted to rise to 1.1 million Canadians in 2038. A lack of dementia awareness has been identified by McCormick Dementia Services. This study examines the current dementia knowledge of a small cross-section of post-secondary students in London, Ontario. A sample size of twenty-eight participants took an online survey in which students identified that they were able to recognize and had sufficient knowledge of dementia. The survey revealed that although adequate knowledge of dementia was present, the participants were unaware of various resources that could be found in their community to further educate themselves outside of the Alzheimer Society. 100% of students think it would be valuable to learn more about dementia. The participants' expressed that if a youth and dementia education one-day symposium were offered, they were willing to attend on their own accord to further educate themselves. The survey indicated a demand for more opportunities to be made accessible for students to get involved and to gain further understanding of dementia. A more comprehensive study is recommended to reevaluate post-secondary student's interest in a youth and dementia education one-day symposium.

Introduction – Context

Dementia is a chronic and progressive syndrome characterized by the disturbance of multiple brain functions (Alzheimer Society of Canada, 2010). As of 2008, an estimated 500,000 Canadians will have a dementia diagnosis and is predicted to rise to 1.1 million Canadians in 2038 (Alzheimer Society of Canada, 2010). Currently, there is a stigma surrounding dementia which is causing difficulties in delivering proper care through education in preventing, identifying, and diagnosing (Alzheimer Society of Canada, 2010). Moreover, if the stigma is not reduced, it will cause a major impact on the individual with dementia, the person's family and caregivers, as well as on health providers, the health care system, the business community, and society (Alzheimer Society of Canada, 2010). Fortunately, McCormick Dementia Services, a well-established community partner in London, Ontario, is committed to conduct support and engage in research activities that enhances the lives of people living with dementia and their caregivers (McCormick Care Group, 2019). Furthermore, Karen Johnson, the Director of McCormick Dementia Services, has proposed to provide a youth and dementia education one-day symposium, a concept created by Spare a Thought for Dementia, in hopes of increasing youth awareness of dementia (Spare a Thought for Dementia, 2019). However, a baseline is needed to know the current dementia knowledge of youths and if they would be interested in a symposium before moving forward. Due to funding and time constraints, the present study will specifically focus on dementia education: what are the needs of post-secondary students in London, Ontario.

Introduction – Literature Review

“The Alzheimer Society is the leading, nationwide health organization for people affected by dementia in Canada” (Alzheimer Society of Canada, 2010, p.2). The Alzheimer Society has identified that delivering proper care for those impacted by dementia is a major concern, which resulted in a two-year intensive project called the *Rising Tide: The Impact of Dementia on Canadian Society* (Alzheimer Society of Canada, 2010). As of 2008, the project has identified about 500,000 Canadians have a dementia diagnosis, which is costing the healthcare system an estimated \$15 billion and around 231 million hours of informal care (Alzheimer Society of Canada, 2010). By 2038, these number will increase to about 1,100,000 Canadians, \$153 billion and 756 million hours (Alzheimer Society of Canada, 2010). To address these issues, the *Rising Tide* has identified best practices, polices and strategies from across Canada and around the world (Alzheimer Society of Canada, 2010). Through much data interpretation, 4 specific interventions in prevention (increase in physical activity and a program to delay dementia onset) and support (caregiver development and support programs and system navigator) were formulated to reduce the impending monetary costs (Alzheimer Society of Canada, 2010). Overall, a framework for government policy was created to help guide the Government of Canada in developing polices to improve the lives of people living with dementia.

The Government of Ontario is responsible for the administration and delivery of local services for all Ontarians (Ontario, 2016). Currently, the Government of Ontario is one of the leaders in Canada to address the issues regarding all aspects of dementia, which include care and education (Ontario, 2016). After collecting data from eight specific communities/organizations such as the Alzheimer Society, a discussion paper called *Developing Ontario’s Dementia Strategy* was created in hopes to “improve access to quality care for people living with dementia

and support those who care for them” (Ontario, 2016, p. 3). Based on the results, six key themes were identified to guide the development of Ontario’s dementia strategy: supports for people living with dementia; accessing dementia services; coordinated care; supports for care partners; well-trained dementia workforce; and awareness, stigma and brain health (Ontario, 2016). Furthermore, the themes were further subdivided into three categories which included: what we heard, issues to consider, and what do people think (Ontario, 2016). These themes were very generalized. However, this was done intentionally to allow Ontarians time to develop their own best practices, which may be used in the future, when Ontario implements their dementia strategy.

To support Ontario’s dementia strategy, Dr. Kristine Newman, an Associate Professor at Ryerson University, has created a program called Spare a Thought for Dementia (T4D) (Newman, Duong, & Kahlon, 2018). The overall goal of T4D is to target youths to raise awareness of dementia in their community (Newman, Duong, & Kahlon, 2018). To learn what youths would be interested in, a youth symposium was conducted which included youths, individuals with dementia and their caregivers, researchers and other non-profit organizations from across the world (Newman, Duong, & Kahlon, 2018). Four outcomes were identified from the youth symposium. This included: exchanging knowledge of dementia; identifying gaps in existing dementia knowledge; establishing collaborative cross-sectorial and intergenerational networks and partnerships; and disseminating key messages to increase youth awareness (Newman, Duong, & Kahlon, 2018). Based on the results of the youth symposium, T4D has identified the usage of social media, in the form of posting Instagram stories, to share youths’ experiences with dementia as an effective strategy to increase youth awareness of dementia (Newman, Duong, & Kahlon, 2018).

Methods – Study Design

To ensure ethical standards, the Fanshawe College Research Ethics Board approved the research design on February 13, 2019. This cross-sectional, descriptive study utilizes a mixed-methods data collection. Furthermore, 14 (yes-no, Likert scale, open-ended) questions based on the literature review was developed (please see Appendix B for the questions).

Methods – Setting & Participants

Through SurveyMonkey, an online survey was created to optimize the greatest number of participants as well as to distribute and to collect the results promptly. The online survey was attached with a consent form (Appendix A), which participants must agree upon before accessing the research study. The inclusion criteria are: being between the ages of 18 to 33, a Western University or Fanshawe College student, and must agree to the consent form. The exclusion criteria are: being under the 18 and over the age of 33, not a Western University or Fanshawe College student, not agreeing to the consent form and not completing the online survey. The online survey was distributed over a 3-week period through mass email to the Western University and Fanshawe College Facebook group, which consisted of about 2000 and 5000 members respectively. Furthermore, the consent form highlights that participating in the online survey will be voluntary and the students are able to quit any time by closing the online survey. In addition, participants will remain anonymous, confidential and risk free with no compensation. However, it is expected that upon completion of the online survey, participants may experience altruism.

Methods – Measures

Data will be stored in a secure online server at McCormick Dementia Services and tracked on SurveyMonkey. Only Karen Johnson and the Principle Investigator will have access to the data. Utilizing descriptive statistics, the data will be interpreted in a table, bar and/or pie chart. Furthermore, the themes, will be presented as WordArt. However, upon completion of the capstone project, the results will be disseminated through an academic research paper and poster presentation at the Fanshawe College Gerontology Interprofessional Practice symposium, shared to the McCormick Care Group Board, newsletters, and presentations to other community support services. Individual data will be guarded against misuse by third party by being kept in a locked, secured location. However, data will not be destroyed and may be used by the organization for future studies. It must be noted that the online survey is hosted by SurveyMonkey in which the data will be stored and accessed in the U.S.A. Furthermore, absolute confidentiality cannot be guaranteed as it may be required by law to disclose certain information to relevant authorities.

Results – Outcomes

Overall, 32 participants completed the online survey but only 28 students met the inclusion criteria. The participants characteristics are summarized in Table 1. In addition, Table 2 outlines general dementia questions that the stakeholder would like to know but requires further research on. However, the most important questions that the stakeholder wants to be investigated will be represented into the figures. Figure 1 illustrates about 90% of the students had sufficient knowledge of dementia. Additionally, Figure 2 shows about 20% of the participants were aware of local dementia resources but were only able to identify the Alzheimer Society. Furthermore, Figure 3 highlights 100% of students think it would valuable to learn more about dementia. In addition, Figure 4 shows about 90% of surveyors expressed that if a youth and dementia

education one-day symposium were offered, they were willing to attend on their own accord to further educate themselves. However, Figure 5 illustrate the 10% of students will not participate in a youth and dementia education one-day symposium unless the issues cost, followed by time and location is addressed. Finally, if a youth and dementia education one-day symposium were offered, Figure 6 shows that students would want to learn about, the signs and symptoms, the risk factors, treatment options and local resources for dementia. Lastly, of the themes identified by the participants, Figure 7 illustrates more dementia awareness is what many surveyors want to see offered at a youth and dementia education one-day symposium, followed by how to decrease stigma of dementia and volunteer opportunities.

Results – Presentation

Table 1: Participant Characteristics (n=28)

Characteristic	Category	n
Gender	Female	22
	Male	6
Age	18-25	24
	25-33	4
Academic Institution	Western University	15
	Fanshawe College	13

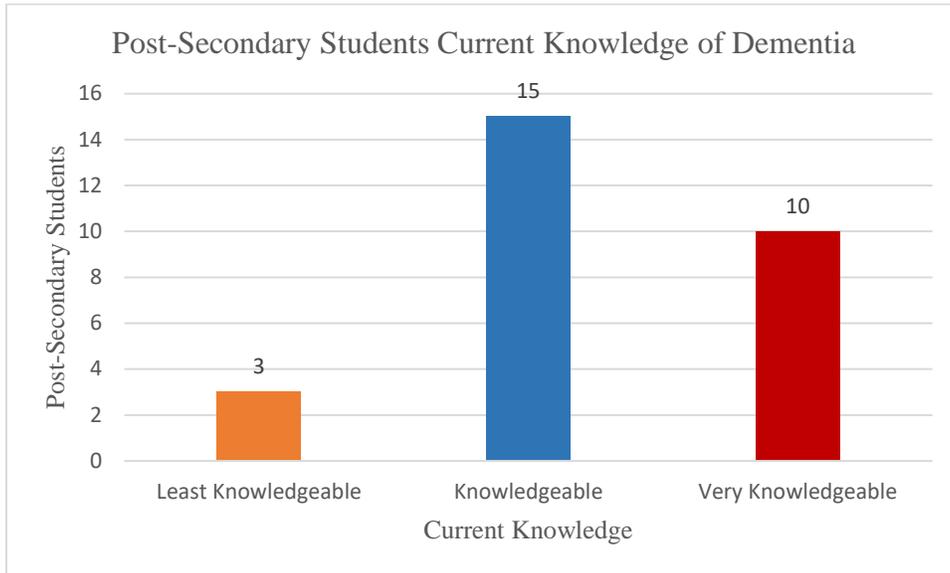
(Exclude # 17, 21, 22, 29)

Table 2: General Dementia Questions (n=28)

Question	Category	n
Do you have a close friend or relative who has Alzheimer Disease or some other form of dementia?	Yes	11
	No	17
Have you ever taken any classes or training regarding Alzheimer Disease or dementia?	Yes	16
	No	12
Are you aware that there is a stigma of dementia?	Yes	19
	No	9
Do you feel this stigma affects your opinions or thoughts of those who have a dementia diagnosis?	Yes	1
	No	27
Are you aware that in 2008, an estimated 500,000 individuals in Canada will have a dementia diagnosis, and that it is predicted to rise to 1.1 million Canadians in 2038?	Yes	24
	No	4
Are you aware of the potential impact of this increase in dementia on the health care system and labour force?	Yes	20
	No	8

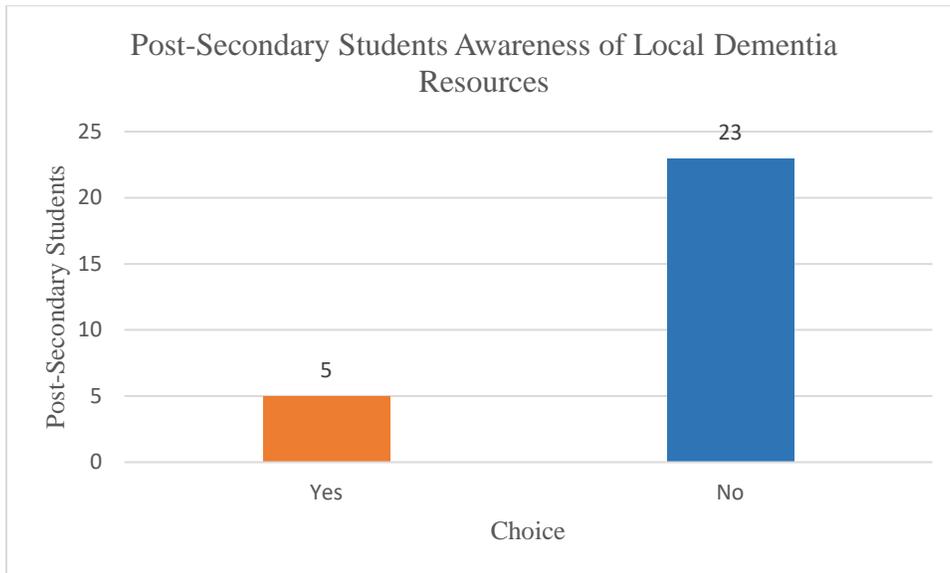
(Exclude # 17, 21, 22, 29)

Figure 1



Sufficient Knowledge

Figure 2



Identified: Alzheimer Society

Figure 3

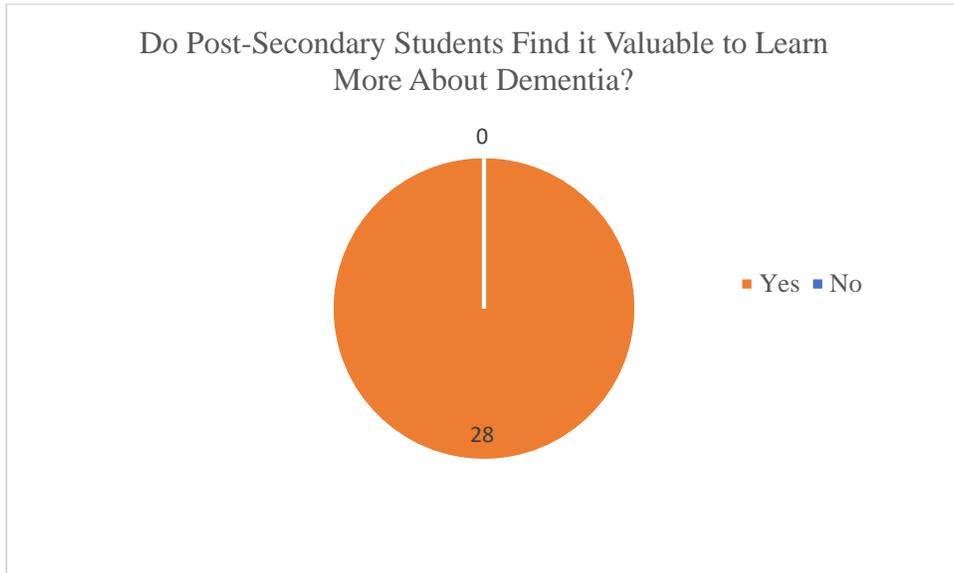


Figure 4:

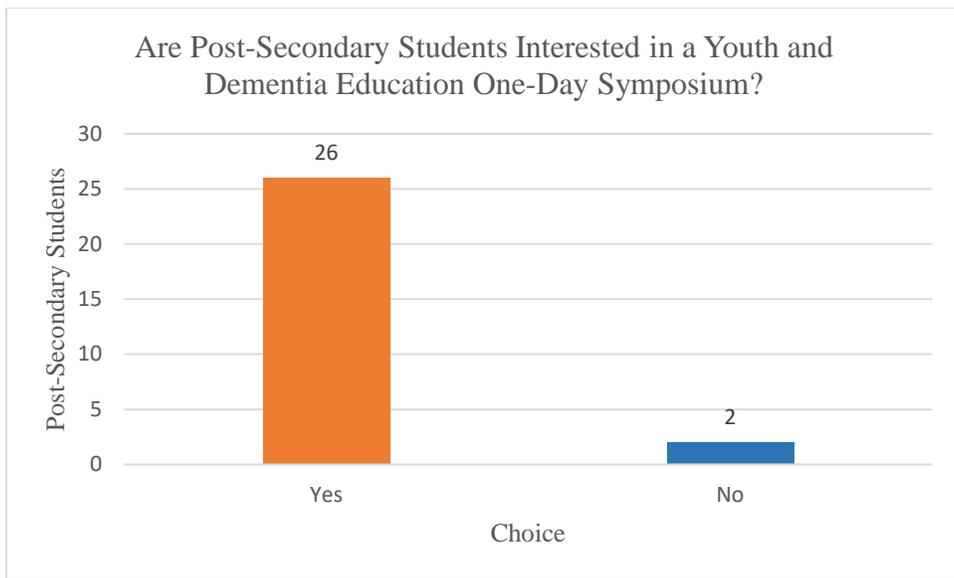


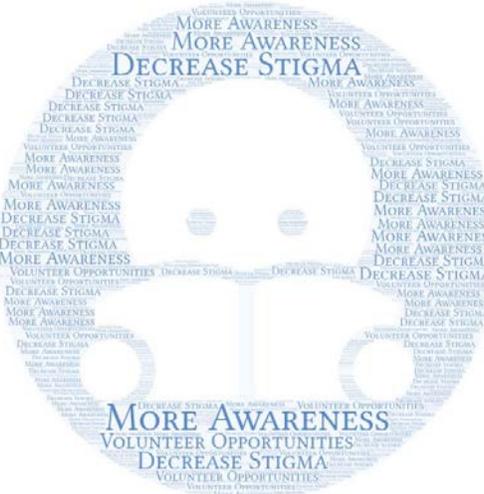
Figure 5: Barriers to a Youth and Dementia Education One-Day Symposium



Figure 6: What Would be Important to Learn?



Figure 7: Top 3 Things Important to Learn



Discussion – Significance

The overall goal of the study was to find the baseline needs of the current dementia knowledge of youths and if they would be interested in a symposium was obtained. Moving forward, Karen Johnson should be able to initiate the next phase of her study, but a few limitations must be addressed. After interpreting the data, many post-secondary students have identified having adequate knowledge of dementia. However, due to the way the questions were phrased (yes/no), there may be an inflated perception of knowledge from participants given they are simply stating “yes”. Furthermore, it cannot be determined where the participants received their knowledge of dementia came from. It is possible that the students did not learn about dementia in their academic institution but from unreliable sources. Perhaps wording the question differently, providing a multiple-choice type question or opened-ended question, might have been better to identify if the responders truly understood the prevalence and cost of dementia or its impact. As stated in the literature review, there is a lack of dementia awareness. However, what may be seen in the study is that the participants lack awareness regarding dementia services/resources since they can only identify the Alzheimer Society and not dementia awareness in the broader sense. It would be difficult to say that these participants do not have awareness of dementia given the fact that they have a professed high level of dementia knowledge. More information needs to be known about the participants before making a definite judgement. Fortunately, a youth and dementia education one-day symposium shows great promise to increase awareness of dementia. An outstanding 100% of students would be willing to learn more about dementia. Furthermore, if a youth and dementia education one-day symposium was offered, the topics of how to increase awareness, how to decrease stigma and volunteer opportunities for dementia is top priority. Nonetheless, the issue of cost, time and

location must be identified before moving onto the next steps. Hopefully, soon, a youth and dementia education one-day symposium would be offered in London, Ontario. If it is successful, maybe, it can be apart of the Ontario Dementia Strategy.

Discussion - Limitation and Recommendation

As mentioned before, to increase awareness of dementia and possibly having a youth and dementia one-day symposium is the end goal of McCormick Dementia Services, many limitations must be addressed before moving forward. Firstly, funding and time constraints is a huge issue. The ideal research method for this study, was not conducted. Other than online surveys, focus groups and one-on-one interviews is a must to require in-depth data. Although the online survey was great to optimize the greatest number of participants, quickly distribute and collect the results, there were many issues. Secondly, the stakeholder wanted a sample size of 50 participants was not reached. This was possibly due to the nature of online surveys. Since there was no incentive, there was no reason for students to participate other than having an interest in the topic. Furthermore, since those who participated did have a general interest in the topic, this may have skewed the results since the students may have received a high level of education regarding dementia. Maybe having each student be entered in a draw to win a gift card could be ideal to get more participants.

The questions that were asked was not validated by experts within the field. In addition, a test group was not administered the survey to further validate the questions asked. Another issue with the questions asked was the lack of detail in the open-ended questions. Usually, there would be one or two points given. If a focus group or one-on-one interview was conducted, again, more in-depth information may have been collected.

Possibly having one-on-one interviews with organizations such as the Alzheimer Society of London and Middlesex, as well as T4D would be a great way to see how they promoted their programs. The students had identified the Alzheimer Society as a great local dementia resource. Furthermore, T4D has successfully conducted a youth symposium. If possible, getting the information on what steps they needed to take to create a youth symposium is highly beneficial.

As mentioned before, the method of online survey was not ideal to get participants. However, maybe next time, posters could be made and posted across the Western University and Fanshawe College campus. Maybe when students walk by, the posters will peek their interested and possibly want to participate in the study. Although a little bit intrusive, maybe going to each classroom and announcing the survey could be possible. Also, setting a booth somewhere on campus that has a lot of traffic could possibly get more participants. Possible times to have a booth is during the beginning of club's week, mental health week, etc.

Another limitation of the study is the lack of diversity of participants and not being able to use all data collected because of the exclusion factor. Due to the exclusion factor, four of the participants' data was not usable because they were from a different academic institution or over the age of 33. Possibly having a broader criterion such as students under the age of 18 could be a possibility. However, ethical approval must be considered since the study will be conducted with minors. Those under the age of 18 must get their legal guardian to consent before collecting data. In addition, instead of just Western University and Fanshawe College students, possibly including all post-secondary students such as those from McMaster University or Mohawk College could increase the number of participants. However, by using data from other academic institution, it must be asked if the participants would be willing to travel to London, Ontario to attend a symposium. Furthermore, there was a huge disparity of males (21%) and females (79%)

in the study. This could possibly skew the results with gender bias. Also, there was no ethnic considerations when creating the studies. Moreover, there is a high possibility of selection bias. Those from the Gerontology Interprofessional Practice program also had the opportunity to participate in the online survey. These students are very knowledgeable about dementia. Although each survey was anonymous, based on the results, some of the students could have participated. Finally, there is a lack of inferential statistics. By utilizing inferential statistics could increase the validity of the study.

Overall, a more comprehensive study to re-evaluate post-secondary student's dementia knowledge should be conducted before creating a youth and dementia one-day symposium. For future research, participants should be involved in a focus group to provide feedback regarding what they learned and what they would like to know more about dementia. Furthermore, the information collected from the focus group can be used for a trail run for a symposium pilot. This will allow the researcher to ask specific questions on what the target audience wants such as the different types of dementia or the signs and symptoms of dementia. Also, this will help the stakeholder decide what topic of interests are needed for a full-scale youth and dementia one-day symposium.

Conclusion

In conclusion, post-secondary students identified that they were able to recognize and had sufficient knowledge of dementia. Although adequate knowledge of dementia was present, the participants were unaware of various resources that can be found in their community to further educate themselves outside of the Alzheimer Society. However, students think it would valuable to learn more about dementia. The participants' expressed that if a youth and dementia education one-day symposium were offered, they were willing to attend on their own accord to further

educate themselves. The survey indicated a demand for more opportunities to be made accessible for students to get involved and to gain further understanding of dementia. Nevertheless, the issue of cost, location and time must be addressed before conducting a youth and dementia education one-day symposium. A more comprehensive study using a different research method is recommended to reevaluate post-secondary student's dementia knowledge. In addition, possibly conducting a small-scale youth and dementia education workshop would be ideal to find out what topic areas will need to be considered for a full-scale youth and dementia education one-day symposium.

Acknowledgements

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Appendices

Appendix A – Consent Letter

**Raising Youth Awareness of Dementia Survey**

Dear University/College Student,

I am currently involved in a collaborative research project with Karen Johnson, the Director of McCormick Dementia Services. All students from an Ontario University/College are formally invited to be involved in this research study by participating in an online survey. Please click on the link below to participate. Please submit your responses by **March 22, 2019**.

<https://www.surveymonkey.com/r/9JLKTQH>

Those who volunteer to be a part of the study will be questioned regarding raising young adult awareness of dementia and reducing the stigma of dementia. As a participant in the study, you will be asked a series of questions. Participants will be asked to complete a very short 14 (yes-no, scale, and open-ended) question online survey.

Please note that any “evaluation” of knowledge carried out during this study exercise are in no way connected to current course grades or program standing, and all data collected are anonymous with respect to personal information. You may refuse to answer any questions or withdraw your participation at any time. Data will only be accessed by Tri Le and Karen Johnson. Additionally, all information collected will be safeguarded under lock and key at McCormick Dementia Services.

Your participation will involve one session of approximately 5-7 minutes and the total number of participants will be determined during data interpretation. Your session will be accessed by a Survey Monkey link. You will be required to have access to a computer with reliable internet. There will be no compensation. Thank you in advance for volunteering to help with this research study.





If you have any questions, please contact the study Principle Investigator Tri Le (t_le5@fanshaweonline.ca). Please include the words "Research Study" in the subject line of any emails regarding questions you may have and thank you in advance for your participation.

We strive to ensure the confidentiality of your research-related records. Absolute confidentiality cannot be guaranteed, as we may be required by law to disclose certain information to relevant authorities.

Please note that the online survey is hosted by "Survey Monkey" which is a web survey company located in the U.S.A. All responses to the survey will be stored and accessed in the U.S.A. This company is subjected to U.S. laws. If you choose to participate in the survey you understand that your responses to the questions will be stored and accessed in the U.S.A. The security and privacy policy for Survey Monkey can be viewed at SurveyMonkey.com

Tri Le, BHSc.
Post-Graduate Student
Fanshawe College

Karen Johnson, MSW, RSW
Director
McCormick Dementia Services



Appendix B – Survey Questions

Raising Young Adult Awareness of Dementia

1. Age
2. Gender
Male/Female/Other
3. Academic Institution
Western University/Fanshawe College/Other
4. Do you have a close friend or relative who has Alzheimer Disease or some other form of dementia?
Yes/No
5. On a scale of 1-10, rate how knowledgeable you feel regarding Alzheimer Disease or Dementia? (1 being least knowledgeable, and 10 being extremely knowledgeable)
1 (least knowledgeable) -----5 (knowledgeable) -----10 (extremely knowledgeable)
6. Have you ever taken any classes or training regarding Alzheimer Disease or dementia?
Yes/No
7. Are there any Alzheimer Disease or dementia resources you are aware of?
No/Yes (please explain)
8. Are you aware that there is a stigma of dementia?
Yes/No
9. Do you feel this stigma affects your opinions or thoughts of those who have a dementia diagnosis?
No/Yes (please explain)

10. Are you aware that in 2008 an estimated 500,000 individuals in Canada will have a dementia diagnosis and is predicted to rise to 1.1 million Canadians in 2038?

Yes/No

11. Are you aware of the potential impact of this increase in dementia on the health care system and labour force?

Yes/No

12. Do you think it would be valuable to learn more about Alzheimer Disease or dementia?

13. If a youth and dementia education one day symposium were offered, would you consider attending?

Yes/No (please explain)

14. If a youth and dementia education symposium were offered, what would be important for you to learn?