

Research Report: Social Prescribing & Family Caregivers Support

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Abstract

The COVID-19 pandemic has brought unprecedented interruptions to the social, economic, and political order across the globe. These disruptions have been felt by family caregivers who use the Rexdale Community Health Centre's social prescribing support programs and services. This study, done in collaboration with Rexdale Community Health Centre (RCHC), adopted a qualitative methodology to investigate the impact of the COVID-19 pandemic on the role, mental, and physical health of family caregivers in the Rexdale community. Also, to examine the impact the COVID-19 pandemic has on support for family caregivers and the types of social support they need, a purposive sampling method was used to select four family caregivers who were engaged through semi-structured phone interviews, which were transcribed and analyzed using the thematic analysis method. The findings indicated that the pandemic affected the mental and emotional health of most participants. The pandemic also impacted the participants' time for self-care and access to social prescribing support programs and services due to lack of time because they were too busy caring for their family members. Based on the findings, the researchers recommend that in-home support, such as personal support workers to assist family caregivers with a sick family member and regular check-in calls to check on how they are coping and their general wellbeing, will be beneficial to family caregivers.

Acknowledgements

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First and foremost, we want to thank our Almighty God for the wisdom, courage, peace of mind, and good health that he has bestowed upon us to complete this research project.

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Introduction

Social prescribing, which started in England in the 1990s is gradually spreading across to other countries such as New Zealand and Canada. "Social prescribing - sometimes called community referrals - is a means of enabling primary care services to refer patients with social, emotional or practical needs to a range of non-clinical services"(Clements-Cortes, 2019). It is an approach that seeks to support and address people's health needs using a broader lens, knowing that there are various factors that determine the health and wellbeing of an individual.

In the summer of 2018, Rexdale Community Health Centre (RCHC), a non-profit organization located in the City of Toronto in Rexdale, North Etobicoke was one of the 11 community health centres across the Province of Ontario that participated in a research project spearheaded by the Alliance for Healthier Communities to examine the efficacy of Social Prescribing. According to a progress report from Alliance for Healthier Communities published in June of 2019, "Social prescribing is a simple yet transformative way of supporting patients' health and well-being by responding to their need for social connectedness" (Alliance for Healthier Communities, 2019). Rexdale Community Health Centre used social prescribing in the following ways: Providing a box of food every two weeks to some families and seniors clients who identified as food insecure and also sending families/family caregivers for a visit either to Ripley's Aquarium, the Art Gallery of Ontario (AGO) or the Royal Ontario Museum (ROM). They did this to see how these new initiatives would improve the mental and physical health of program participants.

Over time, from when the pilot project started in the summer of 2018 to when it ended in 2019, Rexdale Community Health Centre (RCHC) noticed the positive impact of providing a box of food every two weeks and sending families/family caregivers for a visit either to Ripley's

Aquarium, the AGO or ROM had on the general health of family caregivers and seniors who participated. To determine the effectiveness of the two social prescribing pilot programs for seniors and family caregivers, Rexdale Community Health Centre (RCHC) used the data they collected from questionnaires filled by participants before starting the programs and at the end of these programs. Also, Rexdale Community Health Centre (RCHC) used conversations/comments with seniors and family caregivers who participated in these programs to evaluate the impact of the programs. The result from these evaluations shows how social prescription can help to support the mental and physical health of family caregivers, which in turn enables them to perform better in their roles. The social prescribing pilot project ended last year, but Rexdale Community Health Centre (RCHC) has continued to offer Food Boxes to seniors and family caregivers in the Rexdale community.

Research Context

The research project was conducted in partnership with Rexdale Community Health Centre (RCHC). Rexdale Community Health Centre is located in Rexdale, North Etobicoke, in the city of Toronto. According to Statistics Canada, 2016 census profile, North Etobicoke has a population of about 118,040 people, with immigrants making up more than 50% of its population (Statistics Canada, 2019). RCHC provides primary health care, chronic disease management, health promotion programs and services for children, youths, adults and seniors in the Rexdale community. The mission of the organization is "Our doors are open to support and advocate for the physical, economic, social and mental health and well-being of our diverse community and partners to improve equitable access to quality care and services" (Rexdale Community Health Centre, 2019). Family caregivers who live in the Rexdale community and are either current or former clients of the Rexdale Community Health Centre are the target group for this study.

Project Focus/Research Questions

The world has experienced a significant change in the way people socialize, communicate and the way people go about their everyday lives since the start of the COVID-19 pandemic. These restrictions, which require social and physical distancing of people, have limited access to in-person services and programs at RCHC. The social prescribing program for senior/family caregivers, such as a visit to AGO, delivered through Rexdale Community Health Centre (RCHC), has now been moved to a virtual platform. The shift from in-person to virtual program delivery and the social and physical distancing have caused much discussion and uncertainty at RCHC, mostly about how this new way of life might be impacting the role of family caregivers in the Rexdale community.

This research which was done in partnership with Rexdale Community Health Centre (RCHC), seeks to investigate and analyze trends we are seeing now, in terms of the impact of COVID-19 around family caregiving in the Rexdale community. Specifically, this study aimed to answer the following research questions more clearly:

1. How is the COVID-19 impacting the role, mental and physical health of family caregivers in the Rexdale community?
2. How has COVID-19 affected support for family caregivers in the Rexdale community?
3. How can social prescribing to support family caregivers be modified and facilitated given the COVID-19 pandemic?

Situating Self as a Researcher

Deborah will be classified in the same social location as a family caregiver because she is a parent herself who has had to take care of her child and herself during this global pandemic.

Though the researcher is a parent, she recognizes that people have several identities; that intersect in various areas of their lives. The researcher acknowledges her privileges as a well-educated young parent with an able body, a career, and the love and support of her immediate family during the pandemic. So, while she may be socially located in the same group as a family caregiver, their lived experiences are significantly different, so the researcher approached the participants from an anti-oppressive frame.

Iffy has no previous experience with this research topic, but has worked with caregivers, people who help vulnerable groups such as homeless men, seniors, and people with mental health issues. Some of these caregivers are taking medications to help them deal with their mental wellbeing or other medical problems. The researcher realised that she had no idea how to better address the needs of these people at work. Social prescribing is a new concept in her workplace, and she not sure how beneficial it is to the population they serve. The similarity between her workplace and RCHC is that they share common objectives of providing support through services for their community members, particularly those who are vulnerable, based on the insightful information gained through this research on social prescribing and family caregivers support at RCHC. To empower caregivers to participate in the programs in order to alleviate loneliness and facilitate relief assistance.

Verena was an outsider since she was not a family caregiver. She was neither a resident of Rexdale and neither did she have a patient at the center. She thus approached caregivers as an expert to learn their experiences and share insights. The research was anti-oppressive because the researcher created a good rapport and made the commitment to the caregivers. However, the researcher felt related to the interviewees because they are from the same Arabic background.

Literature Review

A preliminary literature review shows that past research has been primarily focused on the use of social prescribing before the covid-19 pandemic, where physical and social distancing was not required.

Social Prescribing

Social prescription is essential in handling patients with chronic conditions such as diabetes as it helps in maintaining their sugar levels (Verma, Punyani & Kalra, 2020). It translates to the well-being of the patients as their blood pressure levels are well maintained through engaging activities that reduce their stress levels. Once a patient is referred to a social prescription then, it reduces the chances of inappropriate medication (Thorpe. J, Thorpe. C, Kennelty, Gellad, & Schulz, 2012). This is because it is easier to identify what they are going through and prescribe them an activity that will make them feel better. Social prescription further helps in solving human social problems through the identification of activities they can work well in like participating in charity groups. (Payne, Walton, & Burton, 2020). Pescheny, Pappas, & Randhawa (2018) conducted a systematic literature review to outline several factors that promote and hinder social prescribing in the UK, including the implementation process, workshops, partnerships, resources, and communication. The correlation between promoting factors and barriers was also analysed in their research.

Social prescription aims to support individuals in controlling their health; it considers factors that determine their well-being, including economic, social, and environmental factors (Pescheny, Randhawa & Pappas, 2018). Clients are referred to a range of non-clinical local services, which ensures their mental wellbeing is achieved (Kimberlee, 2015). Rexdale

Community Health Centre is a strong believer in social prescription and the use of it to support and enhance the well-being of clients. Furthermore, social prescription engages in capacity-building programs that empower individuals to achieve their best results in their wellbeing. Social prescription initiatives have been adopted by the UK National Health Service, mainly to integrate social care and health (Carnes et al., 2017). It works by prescribing activities that are non-clinical to improve patient's wellbeing, hence hastening their recovery from any illnesses or challenges they have (Kimberlee, 2015).

Family Caregivers

Family caregivers in this research context are people in a family who provide care for other family members. Angelo, Egan, & Reid (2013) used a nominal group technique, which is a form of a focus group, to understand the stress family caregivers face. According to the authors, the result from their finding shows three prevailing priorities for educating family caregivers: developing practical skills; caring for oneself physically, mentally and spiritually; and knowing what to expect and brace for as the health of the family member declines (Angelo, Egan, & Reid, 2013). Dhavale, Koparkar, & Fernandes (2020) used a qualitative framework method to analyse the challenges faced by patients and their family caregivers during the COVID-19 lockdown, and what could be done to support them. The results from their research were broken down into three sections. The challenges patients face, such availability of medication, feeling isolated, etc. Family caregiver stress, which includes; fear of inadequacy, lack of information and resources, worry about their own health, etc. Lastly the support from the social work team, such as counselling patients, support for both patients and family caregivers.

Project Design

The research method used for this research is qualitative. The number of participants used for this research was four participants. A small sample size was adequate because of the detailed data that was generated from each participant. The demographic of interest in this research project are family caregivers who live in the Rexdale community and are RCHC client.

Sampling/Recruitment

Purposive sampling is the method used for this study. “Purposive sampling is used to select respondents that are most likely to yield appropriate and useful information and is a way of identifying and selecting cases that will use limited research resources effectively” (Campbell et al., 2020, pp. 653-654). The researchers and the community partners chose this form of sampling because to achieve research aims, objectives and get the expected outcomes for this research the sample has to fit certain criteria such as being a family caregiver who lives in the Rexdale community and is a current or previous client of Rexdale Community Health Centre. To recruit participants, Rexdale Community Health Centre (RCHC) identified their clients who are family caregivers in the Rexdale community, informed them about the research, and provided them with details about the capstone research. Participants who were interested contacted RCHC, and verbal informed consent was obtained after the details on the participant consent form were read to them over the phone. The researchers also read the content in the participant consent form and received verbal consent from the participants before starting the interview. Consent Form - Interview (Appendix A)

Data Collection

In this research project, data were collected through one-on-one phone interviews, asking open-ended interview questions. The researchers interviewed 4 participants, with each researcher

conducting 1-2 interviews each. The phone interviews were conducted from February 25, 2021, through February 26, 2021. Each interview took approximately 30 minutes of the participant's time. A translator was provided by RCHC for a participant whose English was not their first language. Also, a phone recorder, note-taking, and otter ai recording application (otter.ai), were used to record the interviews in this qualitative research to enable the researchers to concentrate and listen to the participants during the interview process. Interview question (Appendix B)

Data Analysis

Thematic Analysis: This is a process of “grouping the data into themes that will help answer the research question(s) (Pell Institute, n.d.). Putting the data collected into themes allowed the researchers to make meaning of the data. The researchers chose this method of data analysis because they felt that looking through the data slowly and writing down the themes they discovered as they progressed would enable them to get the best possible results from the data. Also, because most of the questions were open-ended questions, not having a list of codes or themes before the researchers started analyzing allowed them to view the data with an open and unbiased mind.

A combination of Survey Monkey analysis and Microsoft Word was used to code and analyze the data. All the collected data were entered into Survey Monkey to capture respondent answers. The researchers also recorded participants interview responses on Microsoft Word, used the comment feature to create anchor codes based on the research questions, assigned codes to the anchor codes, sorted them into categories, and tallied how many times a code appeared to find common themes to make meaning of the data collected (Methodology Related Presentations - TCSPP, 2016).

Ethical Considerations

Given the current situation of COVID-19, the researchers conducted the research activities remotely using secure interfaces. The secured interfaces include SurveyMonkey account for data analysis that is password-protected, private phone line for phone Interview. The student researcher signed the Student Researcher Ethics Agreement that indicated their compliance with all ethical requirements regarding the study, including confidentiality and privacy (Appendix C). The lead faculty approved the thesis final proposal before students embarked on data collection. The Community Partner Lead and the researchers read the information on the consent form to the participants over the phone, which outlined the research purpose, research process, and the participants' phone rights and privileges such as confidentiality and privacy (Appendix A). The Community Partner Lead and the researchers received verbal informed consent from participants before starting the interview.

Key Findings

In analysing the interview data, the following themes emerged:

Impacts of COVID-19 on Family Caregivers

The data analysis revealed that half of the participants believe the pandemic is affecting their roles as family caregivers. Below are the main themes the research found.

Emotional & Mental Stress: The responses of the participants showed that the pandemic, social distancing and isolation are impacting the family caregivers emotionally and mentally. The family caregivers reported that they are more anxious because they are afraid that something could happen to family members especially the ones with disabilities if they are not actively monitoring and looking after them.

Lifestyle Change: The participants reported that the global pandemic is affecting their daily lives. Before the pandemic, even though they were caring for their family members, they were still able to go out for walks sometimes, meet up with friends and visit other family members. But since the pandemic started, they are always at home because of the social restrictions caused by the pandemic.

Self-Care: According to the response to the questions of hours they dedicate to caregiving weekly and how the COVID-19 has impacted them, most of the family caregivers are neglecting to take time off for self-care because they are too busy caring for their family members. Most of the participants stated they are dedicating 24 hours a day to caregiving, and that they are constantly caring and worrying about the wellbeing of other family members. (See figure 1)

Figure 1

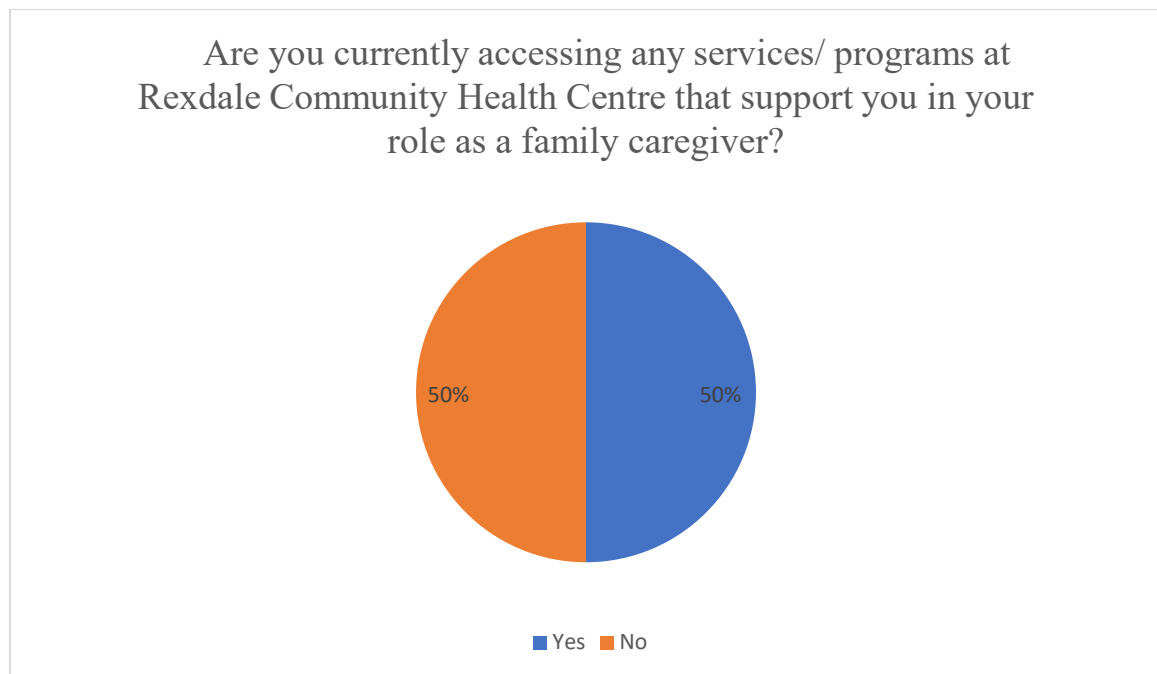
Approximately, how many hours weekly did/do you dedicate to caregiving?

Before the Pandemic	During the Pandemic
23	24
24	24
24	24
24	24

COVID-19 Impact on Support

Lack of Time and Loss of Interest: The findings showed that 50% of the family caregivers were not accessing programs and services to support themselves due to the lack of time to do other things, care for self and the loss of interest in other things because the pandemic is making everything overwhelming. One of the family caregivers stated that “I don’t have time to access any program”, and another participant said that “I am not interested in any other information because it is enough for me only to read the Bible”. See figure 2 for the percentage of participants accessing programs and services.

Figure 2

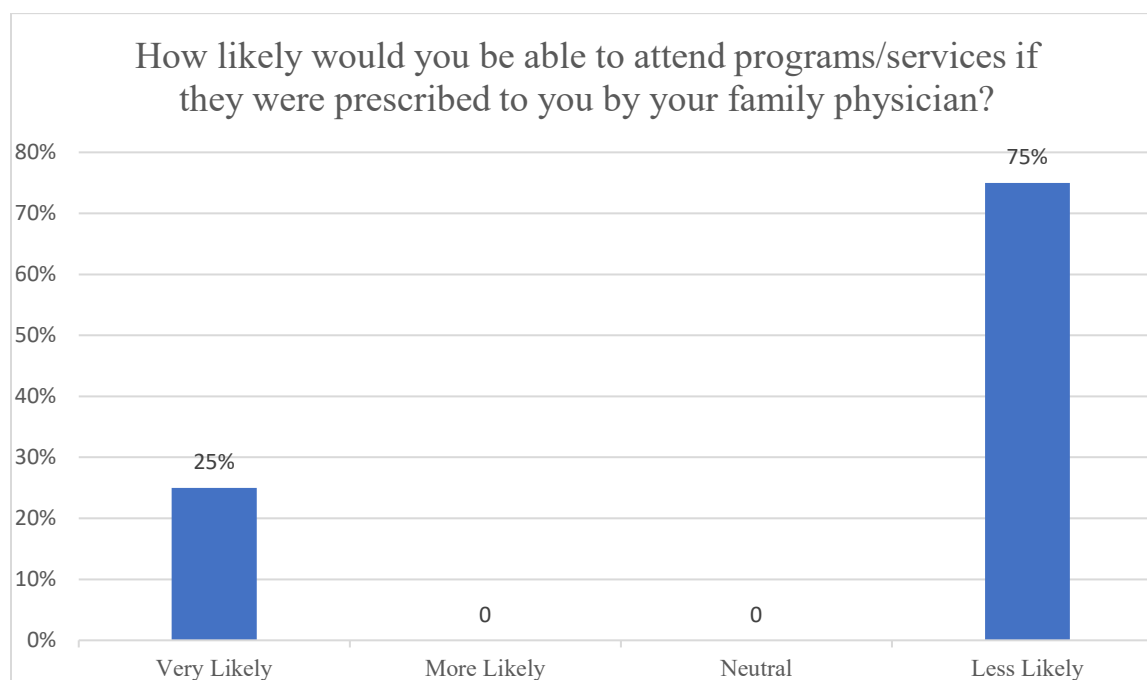


Social Prescribing and Types of Support for Family Caregivers

The finding indicated that most participants were less likely to use online support programs and services even if prescribed to them by their family physician. However, they prefer

face-to-face interaction, support and programs such as external personal support workers for a sick family member and in-home assistance. See Figure 3 for responses to how likely they are to use support programs and services prescribed by their family physician.

Figure 3



Types of Support: One of the participants stated that “I have got to do all the work for my wife, if I can get some help, that will be good. like a support worker would be good”. Another family caregiver stated that the type of support they need is “Getting phone calls, usually to see how I am are doing”.

Contributions/Recommendations

The themes identified from the interview of family caregivers in the Rexdale community indicated that most of the family caregivers were impacted, emotionally, mentally, socially by the COVID-19 pandemic. The findings also provide important directions for support for family caregivers. In terms of support for family caregivers, based on the finding family caregivers will

benefit from in-home support such as personal support worker to assist them with a sick family member, and family caregivers may also benefit from getting routine check-in calls, from RCHC to check on their mental and physical wellbeing.

Limitations

The study had a few limitations, including the setting for phone interviews, the method of data collecting, and bias due to the small number of participants. Since the interviews were conducted through phone calls, the researchers could not learn the respondents' body language. For future research, the number of participants could be increased, and more than one data collection method could be used. The researchers feel that using two or more data gathering methods, such as interviews and focus groups or surveys, and increasing the number of participants, might have resulted in more data for analysis.

Directions for Future Research

Based on the findings and the limitations mentioned above, for future research, the researchers could increase the sample size and use a combination of two or more data collection methods to instigate and compare the mental and emotional impact of the covid-19 pandemic among senior family caregivers and young family caregivers.

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Appendices

Appendix A: Consent Form - Interview

Consent Form - Interview



Social Prescribing and Family Caregivers Support

Dear Participant:

Thank-you for considering participation in this Capstone Project being undertaken by Humber College Community Development Degree students in partnership with Rexdale Community Health Centre (RCHC). Lead from RCHC is Althea Martin-Risden, Director Health Promotion, and Wendy Caceres-Speakman Manager, Services For Seniors RCHC, 416-744-6312 ext 2233.

Should you have any concerns about this research or require any information please contact our research supervisor.

Research Supervisor: Christine McKenzie, PhD., Professor Community Development Degree
416-675-6622 Christine.Mckenzie@humber.ca

This project has received approval from Humber's Research Ethics Board. Persons with broader issues related to ethical concerns can contact The Humber Review Ethics Board Chair, Dr. Lydia Boyko at: 416-675-6622 ext. 79322 or by email at: Lydia.Boyko@humber.ca

Purpose of the Project: This research which will be done in partnership with Rexdale Community Health Centre (RCHC), seeks to investigate and analyze trends we are seeing now, in terms of how the COVID-19 pandemic is impacting family caregivers in the Rexdale community.

Before signing this consent form, please review participation criteria:

- Participation is completely voluntary
- You can opt out of the answering questions at any time if you change your mind
- You are not required to answer all the questions. You can skip questions if you are not comfortable answering them
- Your identity will remain anonymous. Anything you share will be kept confidential by the student and not linked directly to you
- Only faculty supervisors, students and agency partner conducting the interview will have access to raw data
- Results will be reported will be anonymized. That means your responses won't be specifically identified as yours but overall feedback from the group will be shared
- All data collected will be securely stored in a password protected electronic file and destroyed at the end of the project (April 2021)

- Participation will take approximately 45 minutes of your time
- The benefit of participating is the opportunity to reflect. The harm in participating is you may not agree with the responses of others and could be disappointed with the findings

I _____, consent to participating in the Capstone Project. I understand the participation criteria as noted above.

Name of Participant: _____

Signature: _____

Dated: _____

Appendix B: Interview Questions

1. Approximately, how many hours weekly did /do you dedicate to caregiving:
Before the Pandemic _____ During the Pandemic _____

Same Amount _____ Not Sure _____

2. Has COVID-19 impacted your role as a family caregiver?

If **Yes** then ask question Q2 If **No** go to Q3

3. In what ways has the COVID-19 pandemic impacted your role as a family caregiver? For example, mentally, physically, emotionally, and financially?

COMMENT

4. Are you currently accessing any services/ programs at Rexdale Community Health Centre that support you in your role as a family caregiver?

If **Yes** ask Q4 if **No** go to Q5

5. In what ways do these programs/services supports you in your role as a family caregiver during this COVID-19 pandemic?

COMMENT

6. What are the things that get in the way or prevent you from accessing social programs and services?

COMMENT

7. What type of support do you think would be helpful for you at this time?

COMMENT

8. How likely would you be able to attend programs/services if they were prescribed to you by your family physician?

Very likely More Likely Neutral Less Likely Don't Know

9. What day/s and time of the week would you be likely to attend an online or telephone social support programs?

COMMENT

10. Is there anything you would like to add?

COMMENT

Appendix C: Student Research Ethics Agreement**Bachelor of Community Development Capstone Project: Research Ethics Agreement**

I, **[insert student name]**, understand of the content of the Research Ethics Board principles and application to my Capstone Project and agree to comply with all ethical, confidentiality and privacy requirements therein.

In addition, specific Bachelor of Bachelor of Community Development requirements and restrictions are:

- No contact with vulnerable populations on the basis of age, and/or physical and mental abilities/disabilities.
- No physical contact with participants (i.e. no meetings anywhere under any circumstances, whether in an open space such as a park or street, or in a public facility that may be open, or a private residence). All interviews must be conducted virtually with all research participants.
- No contact with Bachelor of Community Development students currently enrolled in the program, or current faculty.

Failure to comply with the foregoing will result in a mark of "0" and the data being confiscated, and the risk of suspension and expulsion from the program. My signature below confirms my agreement to the requirements as described in this agreement.

Investigator's Name (printed)

Investigator's Signature

Date