Peer Similarity and Use of Online and In-person Supports Amongst Adult Children Carers: A Mixed Method Study

by

Marina Bastawrous Wasilewski

A thesis submitted in conformity with the requirements for the degree of Doctorate of Philosophy
Rehabilitation Sciences Institute
University of Toronto

© Copyright by Marina Bastawrous Wasilewski 2016
Peer Similarity and Use of Online and In-person Supports Amongst Adult Children Carers: A Mixed Method Study

Marina Bastawrous Wasilewski
Doctorate of Philosophy
Rehabilitation Sciences Institute
University of Toronto
2016

Abstract

**Background:** Due to current demographics, adult children are increasingly caring for an elderly parent, which can threaten their health. Social support from similar peers can mitigate caregiving-related health declines. Studies have only explored ‘peer similarity’ within the intervention context, limiting our understanding of its role in naturally occurring support. Many carers are turning to the Internet for convenient and efficient access to peer support. Literature to date has largely focused on Internet-based interventions, overlooking carers’ everyday engagement in peer support across communication modalities.

**Objective:** To explore: 1) the relationship between peer similarity and perceived support; and 2) carers’ experiences with online and in-person peer support.

**Methods:** A mixed method study guided by the Interactional Cognitive Model of Social Support. Twitter was used as an innovative recruitment avenue similar to snowball sampling. A web-based survey measured peer similarity and perceived support. Interviews explored carers’ perspectives on peer similarity and experiences with online and in-person peer support. A hierarchical regression analyzed quantitative data and interviews were thematically analyzed.

**Results:** Seventy-one adult children carers (ACCs) participated, with 15 completing qualitative interviews. The mean age of ACCs was 51 and 90% were daughters. Thirty-eight percent of carers were recruited through Twitter and found to be demographically comparable to those recruited through other strategies. ACCs mobilized their existing networks for support and used a blend of communication modalities to meet practical and relational support needs. Type of support received was consistent across online and in-person modalities. Peer similarity positively
and significantly influenced perceived support. ‘Shared caregiving experience’ was described as
the most important aspect of similarity since it was multi-faceted and optimized support and
relationship quality.

**Conclusion**: Interventions for ACCs should emulate their naturally pragmatic support-seeking
style. ‘Shared caregiving experience’ and its various dimensions should be comprehensively
investigated to inform measurement instruments and peer-matching interventions.
Acknowledgments

The completion of my doctoral studies would not have been possible without the guidance and support of my supervisor, advisory committee, friends and family.

First and foremost I would like to thank my wonderful supervisor, Dr. Jill Cameron. Jill—you have always believed in me, encouraged me, and challenged me to go above and beyond the status quo. Whether it was in my presence or behind the scenes, you have been my biggest advocate. I am very grateful for every networking, dissemination and learning opportunity you have facilitated. Above all, I thank you for your mentorship and friendship. You always lead by example and treat your students with the same regard as your colleagues. I look forward to collaborating in the future and seeing your research program continue to thrive.

To my advisory committee members, Dr. Jennifer Stinson and Dr. Fiona Webster—I thank you both for the enthusiasm and expertise you brought to my research. Jennifer—without your insights on eHealth and health technology, my passion and interest in these areas would not have been as nurtured as they were. I am so appreciative of your contributions to both my dissertation and comprehensive exam process. Fiona—your extensive knowledge of qualitative methods was invaluable to the qualitative aspect of my work. I am very grateful for your patience and overall positivity and encouragement.

My doctoral research was generously supported by a number of funding sources that I would like to acknowledge: CIHR Strategic Training Initiative in Health Research (STIHR), Toronto Rehabilitation Institute, Rehabilitation Sciences Institute (RSI), and the University of Toronto’s Faculty of Medicine.

My research on peer support and its value was brought to life through my own need and benefit from my peer group. To my friends and colleagues in the Family Research Group, HCTP program & RSI—thank you for your feedback on my work and for being excellent sources of advice and support. I would also like to extend a most heartfelt thank you to my best friends—Karen, Olga, Yasmin, Leanna and Sabrina. Karen—you’ve been there for me since you were born and now you’ve given birth to the greatest gift. I love you and Noony and am so grateful for the pictures, texts, hashtags and FaceTime calls that kept me laughing throughout my PhD. Olga,
Yas, and Lee—I don’t know what I would do without my Buzzgirls! I am so happy that we have our iMessage group to keep me sane and to remind me of life beyond the ivory tower. Thank you for being the best day ones. Finally to Sabrina—how would I have survived 6 years of graduate studies without you? I am grateful that you have always led the way and been the light at the end of the graduate tunnel. Without our stories, laughs and vent sessions; life would be awfully dull.

I will never know what I did to deserve a family as wonderful as mine. To my parents, Manal & Adel—thank you for you endless support, patience and love. Ever since I was young you made me feel like I was destined for great things. You encouraged me, supported me and walked with me every step of the way. My PhD journey was a long one not just for me but for you as well. My achievements are just as much yours as they are my own. I love you. To my brother, John—in a way, I should be thankful for your endless mocking and prodding; it definitely made me tougher! I am very lucky to have had your support throughout my life. The only thing better than enjoying my own achievements is celebrating yours! To Nonos—thank you for being my prayer warrior! I am so grateful that you hold me in your heart and love me unconditionally. To Teta—it is such a blessing to celebrate this important achievement with my grandmother! Thank you for teaching me to speak English, for showing me what it means to be a tough and determined woman, and for being our angel on earth. I love you so much. To Nana & Bolbol—thank you for being my second parents. I am grateful that you’ve always believed in me. Now you can call me “Dr. B” for real (well…Dr. W, I guess!). To the cousin squad; Mena, Mariam, Monica, Sherief & Danny—you guys are the best. Thank you for supporting me, teasing me, providing endless friendship, and doing it all with the perfect mix of cruelty and love. Finally, to my husband and better half, Mike—getting my PhD is a pretty good achievement but marrying you was the best thing I did in the last 4 years. Thank you for picking up dinners when I was working on my dissertation, for sitting through countless defense practices, for listening to endless ramblings about caregiving policies and practices, and for being the best part of every day. I love you and share this degree as only the first of many things we will celebrate as a team!

Last but certainly not least, I would like to thank the carers that participated in this research. I know you already have so much on your plates and I am truly appreciative of the time you took to provide valuable insights into your needs and experiences.
# Table of Contents

Acknowledgments .................................................................................................................. iv  
Table of Contents .................................................................................................................. vi  
List of Tables ......................................................................................................................... xii  
List of Figures ......................................................................................................................... xiii  
List of Appendices .................................................................................................................. xiv  
List of Definitions .................................................................................................................. xv  

1 Introduction .......................................................................................................................... 1  

1.1 Aging and Caregiving in Canada ....................................................................................... 2  
1.2 Social support for family carers ....................................................................................... 3  
1.3 Peer similarity and its role in peer support exchange ....................................................... 5  
1.4 The Interactional-Cognitive Model of Social Support ...................................................... 6  
1.5 Online and in-person networking between caregiving peers ........................................... 8  
1.6 Summary of Gaps ........................................................................................................... 9  
1.7 Overall Mixed Method Study Objective ........................................................................ 10  
1.8 Research Questions ........................................................................................................ 10  

1.8.1 Chapter 4 (Qualitative: In-person & Online Peer Support) ........................................ 10  
1.8.2 Chapter 5 (Mixed method: Peer similarity’s association with support perceptions) .......................................................... 10  
1.8.3 Hypotheses (For quantitative research questions) ..................................................... 11  

2 Detailed Methods ............................................................................................................... 12  

2.1 Paradigm of Inquiry ....................................................................................................... 13  
2.2 Research Design ........................................................................................................... 13  

2.2.1 Mixed Method Design ............................................................................................... 13  
2.2.2 Quantitative Design ................................................................................................. 14
2.2.3 Qualitative Design ..................................................................................15

2.3 Participants........................................................................................................15
2.3.1 Eligibility Criteria .........................................................................................15
2.3.2 Quantitative and Qualitative Sample Sizes .......................................................16
2.3.3 Recruitment ......................................................................................................17
2.3.4 Procedure ........................................................................................................19

2.4 Data Collection ....................................................................................................20
2.4.1 Quantitative Data Collection ..........................................................................20
2.4.1.1 Situational Factors .....................................................................................20
2.4.1.1.1 Demographics .......................................................................................20
2.4.1.1.2 Caregiving assistance provided .............................................................20
2.4.1.1.3 Care-recipient (parent) dependency ......................................................21
2.4.1.1.4 Geographic Distance ............................................................................21
2.4.1.2 Intrapersonal Factors ..................................................................................21
2.4.1.2.1 Coping ability .......................................................................................21
2.4.1.2.2 Mastery ................................................................................................22
2.4.1.2.3 Extraversion ..........................................................................................22
2.4.1.2.4 Self-disclosure .......................................................................................22
2.4.1.3 Interpersonal Context ................................................................................23
2.4.1.3.1 Contextual information about peer networking ..................................23
2.4.1.3.2 Duration of the peer support relationship ...........................................23
2.4.1.3.3 Frequency of contact between peers ...................................................24
2.4.1.3.4 Peer Similarity .....................................................................................24
<table>
<thead>
<tr>
<th>Section</th>
<th>Title</th>
<th>Page</th>
</tr>
</thead>
<tbody>
<tr>
<td>2.4.1.3.5</td>
<td>Perceived support</td>
<td>24</td>
</tr>
<tr>
<td>2.4.2</td>
<td>Qualitative Data Collection</td>
<td>25</td>
</tr>
<tr>
<td>2.5</td>
<td>Data Analysis</td>
<td>26</td>
</tr>
<tr>
<td>2.5.1</td>
<td>Missing Values</td>
<td>26</td>
</tr>
<tr>
<td>2.5.2</td>
<td>Quantitative Data Analysis</td>
<td>27</td>
</tr>
<tr>
<td>2.5.3</td>
<td>Qualitative Data Analysis</td>
<td>27</td>
</tr>
<tr>
<td>2.5.4</td>
<td>Mixed method data analysis</td>
<td>28</td>
</tr>
<tr>
<td>3</td>
<td>Using Twitter to recruit participants for health research: An example from a caregiving study</td>
<td>30</td>
</tr>
<tr>
<td>3.1</td>
<td>Abstract</td>
<td>31</td>
</tr>
<tr>
<td>3.2</td>
<td>Introduction</td>
<td>32</td>
</tr>
<tr>
<td>3.2.1</td>
<td>Social media &amp; health research</td>
<td>32</td>
</tr>
<tr>
<td>3.2.2</td>
<td>Using social media for participant recruitment</td>
<td>32</td>
</tr>
<tr>
<td>3.2.3</td>
<td>The potential of Twitter for participant recruitment</td>
<td>33</td>
</tr>
<tr>
<td>3.2.4</td>
<td>The heterogeneity of participants recruited through Twitter</td>
<td>34</td>
</tr>
<tr>
<td>3.3</td>
<td>Methods</td>
<td>36</td>
</tr>
<tr>
<td>3.3.1</td>
<td>Design</td>
<td>36</td>
</tr>
<tr>
<td>3.3.2</td>
<td>Participants</td>
<td>36</td>
</tr>
<tr>
<td>3.3.3</td>
<td>Convenience Sampling Strategies</td>
<td>36</td>
</tr>
<tr>
<td>3.3.4</td>
<td>Recruitment via Twitter</td>
<td>36</td>
</tr>
<tr>
<td>3.3.5</td>
<td>Data Collection</td>
<td>38</td>
</tr>
<tr>
<td>3.3.6</td>
<td>Data Analysis</td>
<td>39</td>
</tr>
<tr>
<td>3.4</td>
<td>Findings</td>
<td>41</td>
</tr>
<tr>
<td>3.4.1</td>
<td>Carers recruited via Twitter vs. other convenience sampling methods</td>
<td>41</td>
</tr>
<tr>
<td>3.4.2</td>
<td>Tweets posted</td>
<td>44</td>
</tr>
<tr>
<td>3.4.3</td>
<td>Retweet Activity</td>
<td>45</td>
</tr>
</tbody>
</table>
How does peer similarity influence adult children carers’ perceptions of support from peers? A mixed method study

5.1 Abstract

5.2 Introduction

5.3 Research questions

5.3.1 Quantitative

5.3.2 Qualitative

5.4 Methods

5.4.1 Design

5.4.2 Participants

5.4.3 Quantitative and Qualitative Sample Sizes

5.4.4 Recruitment

5.4.5 Procedure

5.4.6 Quantitative Data Collection

5.4.6.1 Situational Factors

5.4.6.2 Intrapersonal Factors

5.4.6.3 Interpersonal Factors

5.4.7 Quantitative Data Analysis

5.4.8 Qualitative Data Collection

5.4.9 Qualitative Data Analysis

5.4.10 Mixed Method Analysis

5.5 Findings

5.5.1 Participant Characteristics

5.5.2 Hierarchical Multiple Regression: Perceived Support

5.5.3 Qualitative Sample

5.5.4 Qualitative Findings
5.5.4.1 Overriding Theme: Shared caregiving experience is the most important aspect of similarity between caregiving peers ..........93

5.5.4.1.1 Shared caregiving experience strengthens ACCs’ relationships with their peers 95

5.5.4.1.2 Shared caregiving experience optimizes the support received from peers 97

5.5.5 Mixed Method Insights ........................................................................................................98

5.6 Discussion ................................................................................................................................100

5.7 Strengths and Limitations .........................................................................................................102

5.8 Conclusion ..............................................................................................................................103

6 Summary, Integrated Discussion & Implications ........................................................................104

6.1 Introduction ..............................................................................................................................105

6.2 The Present Research ..............................................................................................................106

6.3 Summary of Findings ................................................................................................................107

6.4 Integrated Discussion ...............................................................................................................108

6.4.1 Peer support as it pertains to the adult children carer (ACC) population .................108

6.4.2 The relational aspect of peer support ..................................................................................109

6.4.3 The nature of communication ..............................................................................................110

6.5 Implications .............................................................................................................................111

6.5.1 Theory (Interactional Cognitive Model of Social Support) ..............................................111

6.5.2 Research ..............................................................................................................................113

6.5.3 Practice ................................................................................................................................114

6.5.4 Policy ..................................................................................................................................114

6.6 General Limitations ................................................................................................................116

6.7 Concluding Statement .............................................................................................................117

7 References ...................................................................................................................................118
List of Tables

Table 3-1: Category and number of study-related tweets posted .................................................. 40

Table 3-2: Comparative Analysis & Results ................................................................................... 42

Table 3-3: Retweet Activity ........................................................................................................... 45

Table 3-4: Top 10 most retweeted tweets ..................................................................................... 46

Table 4-1: Participant characteristics (qualitative and full study sample) .................................... 60

Table 5-1: Participant Characteristics ........................................................................................... 90

Table 5-2: Summary of hierarchical regression analysis for variables predicting perceived support ......................................................................................................................... 92
List of Figures

Figure 3-1: Example of a general recruitment tweet ................................................................. 37

Figure 3-2: Twitonomy analytics sample output ................................................................. 38

Figure 5-1: Participant Flow Chart ....................................................................................... 89
List of Appendices

Appendix A: Piloting and evaluating the feasibility of planned recruitment strategy............. 133
Appendix B: Recruitment Brochure .................................................................................. 137
Appendix C: Consent Form ................................................................................................ 138
Appendix D: Visual Summary of Interactional Cognitive Model of Social Support .......... 141
Appendix E: Psychometric properties of original questionnaires ................................... 141
Appendix F: Demographic Questionnaire ......................................................................... 143
Appendix G: Carer Assistance Scale (CAS) ..................................................................... 147
Appendix H: Barthel Index ............................................................................................... 149
Appendix I: Peer support context questionnaire ............................................................... 151
Appendix J: Brief COPE ................................................................................................... 155
Appendix K: Pearlin Mastery Scale .................................................................................. 158
Appendix L: Extraversion Questionnaire ........................................................................ 159
Appendix M: Self-Disclosure Questionnaire ................................................................... 160
Appendix N: Peer-Similarity Questionnaire .................................................................... 161
Appendix O: Perceived Support Questionnaire ............................................................... 163
Appendix P: Scale Reliability Analyses .......................................................................... 165
Appendix Q: Qualitative interview guide ....................................................................... 166
Appendix R: Assumptions of Regression Analysis .......................................................... 170
List of Definitions

**Carer:** An individual caring for a family member without compensation

**Adult child carer:** An adult (18 years or older) who is caring for a parent

**Social Support:** Comprised of emotional, informational, instrumental and appraisal support

**Emotional Support:** Consists of feelings of trust and love

**Informational Support:** Entails providing someone with information or advice

**Instrumental Support:** Refers to the provision of materials to someone

**Appraisal Support:** Characterized by the provision of evaluative feedback to others

**Perceived support:** An individual’s perceptions of satisfaction with support available

**Actual support:** The amount or type of support that was objectively provided to an individual

**Peer:** Another individual caring for a family member

**Online Interaction:** Peer networking that takes place using the internet (e.g. social media, email)

**In-person Interaction:** Peer networking that occurs face-to-face

**Peer similarity:** The extent of overlap between two carers in terms of structural (e.g. demographics), appraisal (e.g. assessment of situations), psychological (e.g. emotions), and experiential (e.g. caregiving experience) considerations

**Shared caregiving experience:** An aspect of peer similarity characterized by overlapping caregiving circumstances between two peers (e.g. caring for a parent also, caring for the same illness population, and being at a similar point along the caregiving trajectory)
Chapter 1

1. Introduction
1.1 Aging and Caregiving in Canada

North America and Europe are presently experiencing a demographic shift towards an elderly population (1;2). In Canada and the United States, 15% and 12.8% of the populations, respectively, are 65 years and older (3;4). The trend in Europe is similar with those aged 65 or older comprising 17.1% of the population (2). With the Baby Boomer generation reaching retirement age, it is estimated that this percentage will rise to nearly 20% in both Canada and the United States by 2030 (3;4) and to nearly 40% in Europe (1). For this growing proportion of elders globally, aging-related illnesses such as stroke, diabetes, chronic obstructive pulmonary disorder (COPD) and cancer are primary causes of morbidity and mortality (5;6).

Due to medical advances, there is an increased likelihood that an individual will survive an adverse event (e.g. stroke) (7;8). However, many still experience long-term physical and cognitive declines that can limit their ability to care for themselves (8). Due to the shift from institutional to community care, elders are increasingly depending on their families for support with daily activities (9). In Canada, over 80% of the care that community-residing elders with disabilities receive is provided by family members (10). As the percentage of those 65 and older nearly doubles in the next 25-50 years, the demand for family caregiving is expected to similarly increase. Family carers not only play an important role in allowing elderly individuals to age at home (i.e. avoid institutionalization) (11), but they also help to sustain our healthcare system. In 2009, the unpaid care provided by family carers in Canada was estimated at over $25 billion (12). In the U.S., this value was a striking $450 billion annually in 2010 (13). For this reason, carers have been called the “invisible providers” (14).

In the past, studies have focused largely on spousal carers of the aging population (15-17). The current demographic trend, however, indicates that for adult children, caring for an
aging parent will increasingly become a likely and normative part of adult children’s lives (18). In the U.S. and Europe, 49% and 30% of all carers are adult children, respectively (19;20). In Canada, 62% of carers over 45 years old are adult children (4). Now more than ever, adult children carers (ACCs) are providing greater amounts of complex care to one or both parents over a longer period of time (18). ACCs are typically at a stage in their lives where they have numerous roles, including being employed, married, and having children of their own. In turn, the parent care role can act as an added stress that exacerbates health declines and the restrictions in social functioning and quality of life experienced by ACCs (21-24).

Although carers are at an increased risk for poorer physical and mental health as compared to their non-caregiving counterparts (25), health declines can be mitigated if carers are well supported in the community (e.g. given access to information, emotional support and instrumental aides). Caregiving support interventions can be broadly categorized into those that aim to reduce burden and distress (thereby reducing long-term adverse impacts on the carer’s health) and those that aim to improve a carer’s competence and confidence (26). Interventions centered on reducing burden typically offer carers respite and counselling in an effort to alleviate caregiving-related distress (26). The majority of carer interventions, however, are psycho-educational. These interventions focus on increasing competency and confidence by providing carers with the educational/informational, emotional, and tangible support they need to better-manage their health and the caregiving situation (26;27).

1.2 Social support for family carers

‘Social support’ is a useful and prominent concept in the caregiving literature as it encompasses the emotional, informational, instrumental and appraisal support that can be provided to carers (28). Emotional support consists of feelings of trust and love; informational
support entails providing someone with information or advice; instrumental support refers to the provision of materials to someone; and appraisal support is characterized by the provision of evaluative feedback to others (28). Studies have highlighted that social support plays an important role in reducing carer depression and improving overall well-being (29;30). The buffering effect model suggests that this is because social support can broaden a carer’s ability to manage their role and in turn, reduce the harm posed by caregiving-related stressors (31). Social support has also been linked to better health behaviors (e.g. those who have social support take better care of themselves than those who are socially isolated) and to less negative affect (e.g., emotional distress) (32).

Studies suggest that while 'actual' support received (e.g. number of times someone helped the individual with a particular activity) (33) is not strongly associated with physical and mental health, 'perceived' support (e.g. individual’s perceptions of satisfaction with support available) (33) consistently promotes health—especially during stressful periods (34;35). In their study, Reindhardt et al (2006) contrasted actual and perceived support and found them to be only mildly correlated ($r = 0.25$, $r= 0.19$; instrumental and affective support, respectively). They also revealed that perceived instrumental support was significantly correlated with well-being ($r = -0.20$, $p <0.01$) while actual instrumental support was not ($r = 0.01$). In light of these findings, it is concerning that interventional research tends not to investigate whether social support interventions change participants’ perceptions of support availability (32).

*Social support from caregiving peers*

Peers—individuals who are also carers and have experienced similar circumstances— are a unique and important source of social support for family carers (31;36). This is largely because the presence of similar circumstances allows for a supportive relationship to ensue out of mutual understanding, empathy and help (31;37;38). These findings are in line with the theory of
homophily which explains that individuals are more likely to establish and maintain supportive relationships with others who are similar to them in important social and experiential dimensions (39;40). This theory particularly applies when individuals such as carers undergo stressful transitions in their lives (38). For example, attendance at peer support groups can enhance carers’ abilities to develop support networks that they can use on a regular basis (41). These networks can in turn offset the negative effects that stressful life events may have on their well-being (42;43).

1.3 Peer similarity and its role in peer support exchange

In non-caregiving contexts, more similarity between peers may strengthen the support relationship (44). ‘Peer similarity’ can be conceptualized as consisting of four major domains: 1) Structural similarity (e.g. demographic similarity); 2) Appraisal Similarity (e.g. perceiving/assessing situations similarly); 3) Psychological similarity (e.g. similar emotional and mental states) and 4) Experiential similarity (e.g. current caregiving experience) (37). Although some studies have begun to investigate the notion of peer similarity amongst carers, most of this work has been interventional in nature.

Interventions that match caregiving peers based on similarities have found only modest improvements in carer health and social outcomes post-intervention (37;45). One study that implemented a ‘befriending’ intervention (i.e. peer mentorship and support) found that it led to minimal improvements in carers’ quality of life and no cost-savings (46). While these findings seem to imply that peer similarity has little value in the caregiving context, it appears that this consensus is limited to interventional studies. In their systematic review of ‘mentoring programs’ for dementia carers, Smith & Greenwood (2014) found that while peer-matching lacked efficacy as an intervention, the qualitative findings highlighted the value that carers
placed on experiential similarity. In turn, they concluded that the importance of experiential similarity and need for matching criteria required further investigation (47). Similarly, Pillemer & Suitor (2002) discussed that future research needed to reconcile the lack of efficacy of their peer matching intervention with the body of literature that suggests that peer similarity promotes well-being in naturally-occurring networks. This highlights the potential value in exploring the role of peer similarity outside of the intervention context in order to gain insight into the role it plays in carers’ everyday support exchanges.

### 1.4 The Interactional-Cognitive Model of Social Support

In order to investigate peer similarity’s influence on perceived support, factors that can confound this relationship must be accounted for. For this reason, we used the Interactional-Cognitive Model of Social Support (ICMSS) to better understand the social support process and the underlying dimensions. The ICMSS particularly lends itself to this study as it uniquely highlights the importance of individuals’ perceptions of support from specific relationships (48). This is in contrast to theories that have previously centralized objective appraisals of support as well as the total size of an individual’s supportive networks (i.e. number of people in their network). The ICMSS suggests that it is not possible to determine if a particular social interaction consists of social support without reference to an individual’s cognitive appraisal of the interaction (49). In this way, the model considers both the social behaviors and cognitive appraisal entailed in person-to-person interaction (48). According to the ICMSS, there are three important dimensions that are central to our understanding of the social support process: 1) situational (e.g. environmental factors); 2) intrapersonal (e.g. person-factors); and 3) interpersonal (e.g. relationship factors) (48).
The *situational context* refers to the social and physical environment in which supportive exchanges take place (48). The aspect of the situational context that has received the most attention in the literature pertains to the presence of *stressors*. The stress-buffering hypothesis asserts that social support can mitigate the impact of stress on an individual’s health and well-being (50). Within the caregiving context, stressful situational aspects can include the dependency of the care-recipient as well as the amount of care that the carer provides (i.e. the tasks to which the carer is oriented) (48).

*Intrapersonal factors* reflect the carer’s predisposition to initiate, engage in and interpret social behaviors (48). The caregiving and social support literature indicates that several personal traits play an important role in carers’ receipt and appraisal of social support. These traits include: mastery, coping ability, extraversion and self-disclosure. ‘Mastery’ refers to carers’ perceptions of self-efficacy, competency and control over life chances (51). Carers who possess mastery over their various roles have reported lower depression over time, less burden, and more life satisfaction (52-54). It has also been suggested that higher levels of mastery are associated with higher levels of social support (55). Coping ability captures the carer’s behavioral and/or cognitive ability to manage situational demands that are appraised as challenging (56). Coping ability has been suggested to buffer the effect of stressful events on carers’ well-being (31) and has been found to be positively associated with perceived social support (57). Extraversion is characterized by an outgoing disposition and high sociability (58). Extraverted individuals are more likely to engage in their social environment and maintain relationships (58); thereby increasing their opportunities to form strong ties with others. Self-disclosure is characterized by an individual’s willingness to provide personal information about their thoughts, feelings and/or needs to another person (58). Individuals who are willing to self-disclose are likely to have more intimate relationships with others over time (58).
The *interpersonal context* captures the distinctive features of both specific relationships and the overall social network in which social support takes place (49). Research has suggested that certain types of support (e.g. tangible, informational) can be limited when individuals are geographically distant from one another (59;60). It has also been theorized that frequent contact between individuals is necessary for healthy and supportive relationships (61). The duration of the relationship also plays an important role as social support processes may change over time (62).

1.5 Online and in-person networking between caregiving peers

Carers are able to seek and engage in peer support in a variety of ways. Traditionally, peer support interventions have been delivered by healthcare and community organizations as in-person support groups. However, due to geographic and time constraints, many carers are unable to meet with their peers in person and are consequently turning to the Internet for this support (63). For this reason, healthcare interventions are increasingly being delivered online due to the Internet’s unique ability to reach a large number of people in a cost-effective and convenient manner (64). These features have simultaneously promoted the development and widespread use of online social support groups (65). For tech-savvy ACCs (i.e. those who regularly use cell phones and have high-speed Internet in their homes (66)), the flexibility of accessing peer support from anywhere and at any time can be especially beneficial given their busy schedules.

It has been argued that the relational and identity cues associated with in-person interaction (e.g. tone of voice, physical appearance, body language) facilitate communication and, in turn, render online interaction as an inferior communication modality for fostering productive relationships between peers (66;67). In light of this position, a great deal of recent literature has aimed to show the value of the online realm by investigating carers’ online support
activity. Analyses of online carer discussion forums indicate that asynchronous Internet interaction can address carers’ inability to attend in-person support groups (68;69). Online interventions have also been shown to positively improve carers’ health and well-being (70;71).

As has been pointed out by Colvin et al (2004), the literature’s focus on evaluating online interventions and analyzing the content of online communication has led to an underrepresentation of carers’ personal experiences with using this modality for peer support exchange. While Colvin et al’s (2004) study on carers’ perspectives of the unique advantages/disadvantages of online social support provides important qualitative insight to address this issue, its focus on the online experience alone does not provide insight into use of other modalities including in-person interaction. To date, studies have largely investigated online and in-person carer peer support in isolation from one another. This approach affords a detailed focus on each modality and provides valuable insights into their unique aspects—e.g. the benefits of peer-led vs. professional-led in-person support groups (41) or the effectiveness of Internet interventions tailored to carers’ worksite or home setting (70;72). However, we only gain a partial understanding of how carers engage in and experience peer support across modalities. This is important as the Internet should be considered only one of many modalities that are used to achieve social and cultural goals as well as maintain relationships (73;74)

1.6 Summary of Gaps

1. A large majority of caregiving research (particularly interventional literature) has focused on the actual support that carers receive rather than their perceptions of support from their peers.

2. Peer similarity has been largely investigated in the context of caregiving interventions. This literature suggests that peer similarity—as the basis for peer-matching and peer-mentoring interventions—does not effectively promote carer health and well-being.
However, we have little insight into the role of peer similarity in carers’ day-to-day peer support activity and its importance in naturally-occurring support networks.

3. To date, the majority of studies investigating carer support delivery have examined *online and in-person modalities* in isolation of one another. Further, research has emphasized evaluation to demonstrate the value of online caregiving interventions or analyzing the content of online caregiving discussion forums. This limits our understanding of how carers seek and engage in peer support across modalities in their day-to-day lives.

1.7 Overall Mixed Method Study Objective

To understand adult children carers’ (ACCs) experience with online and in-person peer support and to explore the influence that peer similarity has on their perceptions of support from peers.

1.8 Research Questions

1.8.1 Chapter 4 (Qualitative: In-person & Online Peer Support)

1. How do ACCs use online and in-person modalities to achieve their peer support goals?

2. What is the nature of peer support exchanged within each modality?

1.8.2 Chapter 5 (Mixed method: Peer similarity’s association with support perceptions)

1. Is an ACC’s perceived similarity with a peer associated with their perceptions of support from that peer? [Quantitative]

2. Does peer similarity account for variation in perceived support above and beyond other variables?[Quantitative]

3. How do ACCs describe similarities/dissimilarities with their peers? How do they perceive similarity with peers to influence their supportive exchanges? [Qualitative]
1.8.3 Hypotheses (For quantitative research questions)

*Hypothesis 1:* Higher perceptions of similarity to a peer will be positively associated with higher ratings of perceived support.

*Hypothesis 2:* Peer similarity will contribute to the variance in perceived support above and beyond other variables (i.e. covariates).
Chapter 2

2 Detailed Methods

This chapter includes a detailed description of the methodological approaches used and presented in abbreviated form in the following chapters (manuscripts written in preparation for publication). This chapter introduces the pragmatic paradigm of inquiry guiding this study. It also describes the overall mixed method approach and its appropriateness to address the study objectives. Included in this chapter is detail pertaining to the specific quantitative and qualitative designs encompassed in the mixed method approach. The study process and participant recruitment are described in detail. The current chapter includes a comprehensive account of the specific quantitative and qualitative data collection (e.g. outcome measures and interviewing) and analysis strategies employed (e.g. regression and thematic analysis). An in-depth description of the mixed method data analysis is outlined (i.e. the way by which the qualitative and quantitative data were compared, contrasted and integrated in order to generate new meaning and understanding). This chapter refers the reader to appended information including study recruitment brochures, study surveys, feasibility evaluation of the recruitment strategy and the missing values analysis.
2.1 Paradigm of Inquiry
This study employed a pragmatic approach. Pragmatism is a paradigm that employs a “what works” philosophy, where knowledge is derived using several approaches and equal value is placed on both objective and subjective knowledge (75). This paradigm differs from positivist approaches that believe in a singular reality with one true truth that can be determined objectively, and constructivist approaches that claim truth is subjective and in turn, multiple realities exist (76). The pragmatic position holds that the research question should be of central importance and will inform the study’s methodological approaches and philosophical worldviews (75). Under the pragmatic paradigm, the researcher is able to abandon the ‘forced-choice dichotomy’ between positivism and constructivism, move beyond the notions of ‘truth’ and ‘reality’ and incorporate a combination of quantitative and qualitative methods that best answer the research questions (77). In this way, mixed method designs are encouraged when two methodological approaches will provide a more comprehensive answer to the research questions (75).

2.2 Research Design
2.2.1 Mixed Method Design
This mixed method study addressed the research objectives by employing a convergent parallel mixed method design (75). Important considerations in mixed method research include the priority of the quantitative and qualitative strands (i.e. dominance of one strand over the other or assigning equal weight), the timing of data collection and the point at which the two forms of data are integrated (75). This convergent parallel design is characterized by the concurrent collection of quantitative and qualitative data, separate analysis of the data sets and integration of the findings at the level of comparison and interpretation (75). Given that the qualitative and
quantitative strands were mixed at the level of objectives, analysis and interpretation, this study can be considered a fully mixed concurrent equal status design (78).

Using a survey methodology, the quantitative strand tested the hypothesis pertaining to the relationship between peer similarity and perceived support (See Chapter 5). Using in-depth interviews, the qualitative strand investigated carers’ perceptions of similarity with peers and how they felt this influenced their peer support exchanges (See Chapter 5). Qualitative interviews also explored carers’ experiences with online and in-person peer support (See Chapter 4). Collecting both quantitative and qualitative data fulfilled two mixed method purposes: 1) Triangulation (i.e. converging the data for greater comparison and validation) and 2) Complementarity (i.e. converging the data for a more holistic understanding of carer relationships and peer support modalities) (79). To achieve triangulation and complementarity, the various dimensions of peer-similarity (e.g. experiential similarity) and perceived support (e.g. perceptions of emotional support) as well as the association between them were compared and contrasted across data sets. This provided insight into whether congruency existed between the dimensions captured by the measurement instruments and those that carers described in their narratives (75). Additionally, the qualitative data provided insight into how carers perceived these constructs to relate to one another and how they influenced their peer support experiences.

2.2.2 Quantitative Design
The quantitative strand of the study employed a cross-sectional survey design. A sample was drawn from the population of interest and all measures were made at one time point with no subsequent follow-up period. This design was ideal for exploring the distribution of variables within our sample and inferring relationships between them (80).
2.2.3 Qualitative Design
The qualitative strand of the study employed a qualitative descriptive approach (81). Qualitative description is a branch of naturalistic inquiry that especially lends itself to studies wishing to make policy or practice changes (e.g. inform intervention development) (82;83). This is largely due to the fact that qualitative description is not highly interpretative and remains data-near (i.e. it provides a concise account of the data that maintains the integrity of the participants’ narratives). Since the findings are presented using non-technical language, they are more easily accessed and applied by policy makers and healthcare professionals (81). Qualitative description importantly differs from phenomenology in that it does not attempt to provide an account of prototypical ‘lived experiences’ across participants (82;84). Unlike grounded theory, the main goal of qualitative description is to provide a concise account of participant narratives rather than use their experiences to build a theory or conceptual model (84). It does, however, employ methodological elements of phenomenology, grounded theory and other qualitative traditions (e.g. data collection and analysis techniques such as saturation, probing, iterative content analysis and thematic analysis) (81;84). Qualitative description can be thought of as a pragmatic process in as far as it applies a ‘what works’ philosophy by borrowing methodologically from other traditions in order to effectively answer the research questions (83).

2.3 Participants
2.3.1 Eligibility Criteria
The target sample for the present study was carers who were engaged in online or in-person peer support activities (e.g. carer forum or support groups, respectively) while being centrally involved in their parent’s care. To be included in the study, participants had to be: 1) 18 years or older; 2) Able to read, write and speak English; 3) Assisting their parent with at least one activity or instrumental activity of daily living (ADL or IADL) at least once a week (e.g. ADL: dressing,
bathing; IADL: managing finances, grocery shopping); 4) Interacting with another carer (either online or in person) and 5) Providing care in Canada. These eligibility criteria reflect revisions made based on a 2-month feasibility evaluation of the recruitment procedures prior to the launch of the full study (See Appendix A).

2.3.2 Quantitative and Qualitative Sample Sizes

For the purpose of the quantitative strand of the study, a non-probabilistic sample was collected (i.e. a convenience sample). Non-probabilistic sampling entails selecting individuals based on their availability to be studied (75). Given that the present study focused specifically on peer-to-peer relationships, sampling needed to occur from a pool of carers who were engaged in peer networking activities and were available/willing to participate during the recruitment period.

A widely recognized rule-of-thumb for calculating the sample size needed for a sufficiently-powered regression analysis is 10 participants per independent variable (85). However, Harrell (2011) has suggested that 8 to 9 participants per independent variable is sufficient for a regression analysis as long as the variables are well-justified by the literature (86). Given that the selection of study variables was rooted in theory, 80 participants (8 participants x 10 independent variables) was deemed sufficient to give the analysis the necessary statistical power.

Qualitative data collection and analysis generally require a smaller sample size than that used for a quantitative study (87). Consequently, we gave participants who completed the online survey an opportunity to volunteer for an in-depth interview and selected a subset of carers from those who were willing. ‘Purposive sampling’ is a strategy used by researchers to ensure the inclusion of participants who possess characteristics or experiences that may contribute additional or differential data to the study (88). Peer interaction modality was an important element of the current study as it was imperative to gain insight into carers’ experiences with
both online and in person peer support. The literature has suggested that the caregiving experiences and responsibilities of sons and daughters differ and that the experience of caring for a mother can differ from that of caring for a father (89;90). Therefore, this study wanted to capture any gender-based differences/similarities related to the peer support process. For the present study, purposive sampling was used—specifically maximum variation sampling—to seek heterogeneity in interaction modality (i.e. online vs. in person), relationship to the care-recipient (i.e. daughter vs. son) and gender of the care-recipient (i.e. mother vs. father) (91). Analysis occurred concurrently with interviewing and we closed recruitment once “theme saturation” was reached (i.e., no new ideas were uncovered in participant interviews) (84;88). Saturation of the purposive categories was also sought and considered to be achieved when the following were equally represented: a) sons and daughters (i.e. carer gender); b) online and in-person communication (i.e. modality); and c) mothers and fathers (i.e. parent gender).

2.3.3 Recruitment

Several strategies were employed to recruit carers. In order to ensure that they would be successful, we piloted the strategies for 1 month prior to commencing the full study. We then evaluated their feasibility and made changes accordingly. The following reflects the updated recruitment approach based on the evaluation (See Appendix A for details of pilot study).

Recruitment brochures were distributed to four community-based carer support groups in four major Canadian cities (Toronto, Halifax, Calgary and Vancouver) (Appendix B). Liaisons at each support group provided carers with the brochure, which had information about the study and the questionnaire web link. Additionally, recruitment information was distributed by St. Elizabeth Healthcare (a national community-care organization) and March of Dimes (a national
non-profit community-based rehabilitation organization) via their provincial coalitions and social media outlets.

The Canadian Virtual Hospice (CVH) website and Facebook page were also used to locate and invite carers to participate in the study. The CVH website has over 25,000 visitors per month, with a rapidly growing population of carers to aging parents (92). The website provides educational content as well as blogs, online support groups and social media engagement. The study was advertised through CVH in 3 ways: 1) advertising in an administrator-monitored forum; 2) link to study on the group’s Facebook and Twitter pages and 3) email to members in ‘eNews’ (5000 subscribers).

Two online carer communities were also partnered with: 1) Family Carers’ Network Society (FCNS) sent study information to their membership via an email newsletter and also posted study posters in their office; 2) Forgetful Not Forgotten (an online network for carers of family members with dementia) allowed us to post study information on their discussion forum.

Twitter was also used to “tweet” the link to the survey along with relevant hashtags (e.g. #carer, #caregiving, #research). The study survey link was also “tweeted” at relevant users (e.g. organizations or community managers) who may “retweet” the link to their own followers. The activity of retweeting is similar to the process of snowball sampling which takes place through word of mouth (Details of this Twitter recruitment strategy are outlined in Chapter 3). A Facebook page was also created and paid Facebook advertisements were posted for a 2-month period. Finally, the primary investigator sent a recruitment email to the Rehabilitation Sector at the University of Toronto (consisting of the Occupational Therapy, Physical Therapy and Speech-Language Pathology Departments).
2.3.4 Procedure

During the recruitment period, all carers who expressed interest in the study (either online or through in-person recruitment methods) were provided with a link to the online survey. FluidSurveys™ (www.fluidsurveys.com)—a secure online survey application that is hosted in Canada—was used. The first part of the survey screened carers for eligibility. Once a carer met the inclusion/exclusion criteria, they were linked to the consent form, which provided in-depth detail about the study as well as potential risks and benefits (Appendix C). Once carers provided their consent, they were directed to the full survey. Since one aspect of our study centered on understanding the experiences of carers who engage in peer support online and in person, carers were asked to indicate the modality in which they predominantly interacted with peers. Based on this response, carers were grouped as either ‘online’ or ‘in person’. Our study aimed not only to investigate carers’ overall peer support experiences but also their exchanges and relationships with specific peers. For this reason, prior to completing the questionnaires focused on the peer support relationship, carers were asked to provide the initials of up to 5 caregiving peers that they interact with in the modality they indicated (online or in-person). The online survey then randomly selected one of these peers for the carer to reflect upon when completing the subsequent questionnaires (i.e. frequency of contact with peer, geographic distance from peer, peer similarity and perceived support). This strategy was used to mitigate the potential bias associated with carers selecting a peer themselves (i.e. carers may have automatically selected their closest or most supportive peer, limiting the potential for variation in the data). Once participants completed the full survey, they were asked if they would like to participate in a qualitative telephone interview. If participants agreed, they were prompted to provide their contact information for follow-up.
2.4 Data Collection

2.4.1 Quantitative Data Collection
Participants were asked to complete a battery of questionnaires that comprised the full survey. The full survey consisted of 126 questions and was estimated to take 30-45 minutes to complete. The constructs that were measured and their associated measurement instruments are described below and organized according to the domains outlined by the Interactional-Cognitive Model of Social Support (Described in Chapter 1) (See Appendix D for a visual summary of the model and variables captured). The measures were previously employed with similar populations and found to be valid and reliable (See Appendix E for psychometric properties of measures).

2.4.1.1 Situational Factors

2.4.1.1.1 Demographics
For descriptive purposes, a demographic questionnaire was administered to participants in order to capture their age, gender, family situation (e.g. marital status, if they have children), caregiving situation (e.g. how long they have been a carer, source of parent’s deficit), cultural background, ethnicity, work status, education level and income level (Appendix F).

2.4.1.1.2 Caregiving assistance provided
Carers completed the Carer Assistance Scale (CAS) (93). This questionnaire consists of 17 items that ask carers to rate the amount of assistance they provide with a variety of activities of daily living (ADL) and instrumental activities of daily living (IADL) on a scale from 0 (‘none’) to 6 (‘a lot’). This measure generated a global score ranging from 0 to 102, where higher scores indicated more caregiving assistance provided (Appendix G).
2.4.1.1.3 Care-recipient (parent) dependency
To capture the severity of the care-recipient's deficits, carers completed the modified Barthel Index (94). This questionnaire established the degree of care-recipient independence by asking whether they are independent, moderately dependent or fully dependent in completing a combination of 10 ADLs and IADLs. This measure generated a score ranging from a minimum of 0 to a maximum of 20, where higher scores indicated more functional independence (Appendix H).

2.4.1.1.4 Geographic Distance
Participants were asked if they knew how far they lived from their peer. Only those that answered 'yes' were subsequently asked if they lived in the same country, province, city and neighbourhood as their peer. Participants could answer “yes” (Scored as 1), “no” (Scored as 0) or “I don’t know” (Scored as 0). Geographic distance between peers was calculated by summing the total score for each participant, where higher scores indicated closer geographic proximity between peers. Participants that indicated they didn’t know how far they lived from their peer (n=12) were excluded from subsequent analyses that included geographic distance as a variable (Appendix I).

2.4.1.2 Intrapersonal Factors
2.4.1.2.1 Coping ability
The Brief Coping Orientations to Problems Experienced (COPE) Inventory was used (95). This is a 28-item self-report measure used to: a) assess coping methods and stress responses in adults; and b) identify specific coping styles and the extent to which an individual relies on them. Participants are asked to rate how often they use various coping methods (e.g. “I’ve been making jokes about it”) on a scale of 1 (“I haven’t been doing this at all”) to 4 (“I’ve been doing this a
lot). We used the problem-based coping subscale (items 2, 7, 10, 14, 23 and 25) and emotion-based coping subscale (remaining questions) in our analyses. This measure generated a score for the problem-based coping sub-scale that ranged from 6 to 24 and from 22 to 88 for the emotion-based coping sub-scale, where higher scores indicated more frequent use of that coping style (Appendix J).

2.4.1.2.2 Mastery
The 7-item Pearlin Mastery Scale was used to assess individuals’ beliefs about the extent to which they are able to control or influence their life chances and outcomes (51). Participants were asked to indicate how much they agree with seven statements on a scale of 1 (strongly disagree) to 4 (strongly agree). Scoring for items 1, 2, 3, 5, 7 were reversed so that higher scores represented more mastery. This mastery measure generated a global score that can range from 7 to 49, where higher scores indicate higher levels of mastery (Appendix K).

2.4.1.2.3 Extraversion
The 4-item Extraversion measure (58) captures the aspect of individuals’ personality characterized by sociability, talkativeness, assertiveness and excitability. Participants rated the extent to which they agree or disagree with each of the following statements: a) “I like to have a lot of people around me”; b) “I really enjoy talking to people”; c) “I like to be where the action is” and d) “I usually prefer to do things alone” (reverse coded) (1= strongly agree and 7 = strongly disagree). Scores ranged from 4 to 28, where higher scores indicated that individuals were more extraverted (Appendix L).

2.4.1.2.4 Self-disclosure
The 3-item Self-disclosure measure captures how likely the participant is to disclose intimate details about themselves (58). This measured asked participants to imagine that they are talking
to someone face-to-face when answering the questions: a) ‘‘I usually talk about myself for fairly long periods of time’’; b) ‘‘Once I get started, I intimately and fully reveal myself’’ and c) ‘‘I often disclose intimate, personal things about myself without hesitation’’. Participants responded based on a 7-point Likert scale where 1= strongly disagree and 7 = strongly agree. This measure generated a global score that ranged from 3 to 21, where higher scores indicated higher levels of self-disclosure (Appendix M).

2.4.1.3 Interpersonal Context

2.4.1.3.1 Contextual information about peer networking

We developed a questionnaire to capture contextual information about carers’ engagement in peer networking (e.g. number of peers they interact with, modality within which they interact, frequency of interaction, etc.). In this questionnaire, carers identified up to 5 peers that they interact with either in person or online depending on the modality they indicated as the one they predominantly use for peer support activity. The online survey then randomly selected one of these peers and participants were asked to answer the following questionnaires based on the randomly selected peer (Appendix I).

2.4.1.3.2 Duration of the peer support relationship

Duration of the peer support relationship was captured by asking participants to indicate the year they started interacting with their peer. This was then subtracted from 2014 (year in which participants completed the survey) to compute the duration of the relationship. One participant entered 1913 as the year that the relationship commenced and this was treated as an entry error since the participant was only 67 years old. This value was replaced with the average relationship duration (11.3 years) (Appendix I).
2.4.1.3.3 Frequency of contact between peers

Frequency of contact between peers was captured on a 6-point Likert scale item that asked participants to indicate how often they interacted with their caregiving peer (0= Less than once a month, 1= once a month, 2= a few times a month, 3= once a week, 4= a few times a week, 5= every day). Higher scores indicated a higher frequency of contact between peers (Appendix I).

2.4.1.3.4 Peer Similarity

The 6-item Peer Similarity questionnaire asked participants to rate their overall similarity to a peer as well as their similarity in terms of values, personality, mood, worries and hobbies (1= Similar to 9= dissimilar) (96). While this is one of few validated questionnaires intended to capture peer similarity, we felt that other relevant domains of similarity were not included. In turn, four questions were added to capture demographic similarity, emotional/psychological similarity, and appraisal similarity as recommended by Sabir et al (2003): 1) This peer is similar/dissimilar to me demographically (e.g. age, gender, marital status); 2) This peer is similar to me in their feelings of self-worth and self-value; 3) This peer is similar to me in identifying positive aspects of caregiving (e.g. satisfaction with caregiving, benefits of caregiving); and 4) This peer is similar to me in finding caregiving to be stressful. One caregiving-specific question was also added: This peer is similar to me in terms of the caregiving situation (e.g. who they’re caring for, amount and type of care provided, how long they’ve been providing care). Scores ranged from 11 to a maximum of 99, where higher scores indicated more similarity with the peer (Appendix N).

2.4.1.3.5 Perceived support

The support subscale of the Quality of Relationships Inventory (QRI) was used (97). The QRI is comprised of 25 items that capture support, depth and conflict in interpersonal relationships. The support subscale indicates the extent that an individual perceives another person to be a source of
assistance across a variety of situations. This subscale consisted of 7 items that asked participants to rate (on a 4-point Likert scale) the extent to which they could turn to/rely on their peer for some sort of support (1=Not at all, 2=A little; 3=Quite a bit; 4=Very much). This subscale generated a total score that ranged from 7 to a maximum of 28, where higher scores indicated more perceived support (Appendix O). (See Appendix P for scale reliability analyses conducted using SPSS).

2.4.2 Qualitative Data Collection
Purposively sampled carers who volunteered from the larger quantitative sample participated in one in-depth interview that was conducted over the phone. Each interview was guided by a set of semi-structured, open-ended questions. The first half of the interview guide overlapped with the quantitative research questions and objectives of the mixed method portion of our study (focused on peer similarity and perceived support). This enhanced our ability to compare and contrast the narrative data from the interviews with the quantitative data from the questionnaires (75). The latter half of the interview guide focused on elucidating carers’ experiences with online and in-person peer support. The qualitative interviews asked participants to describe: a) Their caregiving situation (e.g. who they are caring for, what type of assistance they provide); and b) Their engagement in peer-support activity (e.g. types of peer support provided/received; how long they have been accessing peer support, overall experiences with peer support) (Appendix Q).

To enhance our ability to compare quantitative and qualitative data, the interview guide asked carers to provide detailed descriptions of their relationship and support experiences with the peer that was randomly selected by the online survey software (described above). Carers were specifically asked to describe: a) their perceptions of similarity/dissimilarity to their peer (e.g. components of similarity, how they determine similarity); and b) the role that similarity (or
dissimilarity) plays in their interactions (e.g. how do similarities/differences with peer influence that relationship, their interactions and the carer’s perceptions of support received) (Appendix Q).

For the qualitative focus on online versus in-person experiences of peer support, the interview guide asked carers to provide in-depth descriptions of: a) their experience with online or in-person peer support (e.g. who they interact with, how they interact, their opinions about that modality, why they interact in that modality); and b) the type of support they receive from peers within each modality (Appendix Q). Throughout the course of the interview the “probing” method was used to encourage participants to discuss topics in greater detail – especially when the topics were of relevance to the research questions (98).

2.5 Data Analysis

2.5.1 Missing Values

A missing values analysis was run in SPSS to investigate the extent to which data was missing from the measures capturing the following independent variables: Carer assistance (CAS), care-recipient’s functional independence (Barthel Index), emotion- and problem-based coping (Brief COPE), mastery (Pearlin Mastery Scale), extraversion, self-disclosure, and peer similarity. A missing values analysis also investigated the amount of missing data from the dependent variable perceived support (Support subscale of the Quality of Relationships Inventory). Across all variables, only 0.968% of data were missing (i.e. less than 1% of all questions were unanswered). Each of the individual variables (e.g. peer similarity, perceived support) had less than 4.5% of data missing (i.e. less than 4.5% of each scale’s questions were unanswered). A non-significant Little’s MCAR Test, $\chi^2 (2431)=34.54$, p=1.0, revealed that data were missing completely at random. In turn, missing data were imputed using the Missing Values Analysis.
within SPSS Version 22 (99). When data are missing completely at random and only a very small % of data are missing (<5%), SPSS employs a single imputation using the expectation maximization (EM) algorithm to replace missing data. The EM method provides unbiased parameter estimates and improves statistical power of analyses (100).

2.5.2 Quantitative Data Analysis
Means, frequencies and percentages were used to summarize the demographic characteristics of the sample population. To investigate the relationship between peer similarity and perceived support, a multiple regression analysis was performed. Prior to conducting this analysis, the assumptions of multiple regression were tested (101) (See Appendix R).

A stepwise hierarchical multiple regression analysis was conducted to investigate the relationship between peer similarity and perceived support. This analysis allowed for the investigation of the additional variance in perceived support accounted for by peer similarity alone. The following variables were entered in the first model: frequency of contact with peer, duration of relationship with peer, amount of care provided, functional independence of the parent, self-disclosure, extraversion, mastery, problem- and emotion-based coping. Peer similarity was entered into the second model. This analysis outputted two models with their respective r² values (representative of how well the variables in the model predict perceived support). The change in r² between Model 1 (covariates alone) and Model 2 (peer similarity added) was observed to explore whether Model 2 better-predicted perceived support due to the addition of peer similarity.

2.5.3 Qualitative Data Analysis
Thematic content analysis was performed to identify themes from participants’ narratives (102). This analysis was initiated by doing an open coding of the transcripts and generating first
impressions of the data (102;103). In collaboration with two masters of occupational therapy (MScOT) students, open coding was initiated after 10 interviews were completed. This informed the development of a coding framework which was rigorously applied to all transcripts (102). NVivo version 10 qualitative data analysis software (104) was used to facilitate the coding process. The coding framework and the interview transcripts were uploaded to NVivo. Line-by-line coding using the framework was conducted with each transcript. Subsequent analyses included comparing and contrasting the coded data and categorizing similar ideas. I, my program advisory committee and the MScOT students all participated in the final phases of analysis, which entailed constant comparison to identify broad themes that meaningfully capture the ideas represented in the various categories. This process was iterative and continued until ‘potential themes’ were considered richly detailed and sufficiently distinct from one another (102;103). The involvement of multiple individuals in the analysis process helped to reduce bias and enhance the credibility of the findings (105).

2.5.4 Mixed method data analysis

The ‘yield’ of a mixed method research (MMR) study (i.e. the novelty of the research that goes beyond the sum of its parts) is indicated by the degree of integration between the quantitative and qualitative data sets (106). To ensure high yield in the present study, ‘crystallization’ was employed. This process entailed looking at the convergence and divergence in the data sets through a) data consolidation, b) data comparison, and c) data integration, in order to uncover new ideas that could not have been derived from the quantitative or qualitative data sets alone (107). Through data consolidation, the quantitative results and qualitative findings were combined in order to generate a new understanding of the phenomena at hand (i.e. peer similarity and perceived support). This provided a more in-depth understanding of peer similarity and
perceived support within a caregiving context. During the *data comparison* stage, the quantitative and qualitative findings were compared and contrasted to gain insight into the congruency and discrepancy between the results (108). This allowed me to compare and explore whether the quantitative domains of peer similarity and perceived support aligned with carers’ qualitative descriptions of these constructs. I was also able to explore whether the quantitative relationships between constructs corresponded to carers’ perceptions of their relation to one another. Finally, the *data integration* stage entailed giving an overall account of the data and summarizing novel information gained by integrating the two data sets (i.e. the key ‘mixed method’ take home messages) (108).
Chapter 3

3 Using Twitter to recruit participants for health research: An example from a caregiving study

Citation: Wasilewski, MB; Stinson, JN; Webster, F; Cameron, JI. Using Twitter to recruit participants for health research: An example from a caregiving study. *Journal of Biomedical Informatics* (Under Review, July 2016).
3.1 Abstract

Objectives: (1) To explore whether carers recruited through Twitter are comparable—in demographics and Internet proficiency to those recruited through other convenience sampling strategies; (2) To describe the nature and extent of study-related tweets; and (3) To describe the extent to which tweets were shared by others.

Methods: In a caregiving study, recruitment via Twitter was analyzed. Tweets were posted (Feb 1-Oct 1, 2014) asking users to access and retweet the study survey link. Mann-Whitney and chi-square tests compared carers recruited via Twitter vs. other convenience sampling strategies on demographic variables and Internet proficiency. Z-scores were calculated to estimate effect sizes. Twitonomy was used to aggregate study-related tweets, which were then categorized based on type. We used www.retweet.co.uk to capture the top 10 tweets and associated reach.

Results: Of 71 carers, 27 were recruited through Twitter. No significant demographic or Internet proficiency differences existed between groups. Tweets included general recruitment (n= 124), mention (n= 1275), and engagement tweets (n= 285). General recruitment tweets were most-shared by users (67.2% were retweeted). The top 10 most retweeted tweets indicated that tweet reach can range from 5,273 to 62,144 users.

Discussion & Conclusion: Findings suggest that it is possible to recruit sample populations through Twitter that are comparable to those recruited by traditional means. Although Twitter helped us recruit hard-to-reach carers, researchers should carefully consider whether this strategy is appropriate to recruit other populations of interest. Time must be invested into building followers and rapport on Twitter to enhance credibility and tweet reach.
3.2 Introduction

3.2.1 Social media & health research

In 2014, the estimated worldwide use of social media, such as Facebook, Twitter and YouTube, was 1.79 billion and use is projected to rise to 2.44 billion by 2018 (109). In the 4th quarter of 2014, the international number of monthly active Twitter users amounted to 288 million (109). With staggering numbers such as these, it is not surprising that a discussion about the role of social media in medical and health research has gained traction (110-115). Although a growing number of health researchers are beginning to embrace online data collection and dissemination, the adoption of Internet-based recruitment has been far from rapid (116). Social media sites provide access to a wide network of potential participants (117), highlighting the importance of addressing the underuse and underreporting of this research tool.

In their review on social media use in research, Lafferty & Manca (2015) developed a framework to categorize research studies into those that use social media during the planning, development, implementation and dissemination phases of research. The present paper focuses on the use of social media during the implementation phase of research—specifically, participant recruitment.

3.2.2 Using social media for participant recruitment

Social media has been identified by several studies as being valuable for recruiting research participants (111;113;118). The benefits afforded by social media recruitment include cost-savings (due to reduced travel to various recruitment sites) (116;119), increased recruitment through snowball sampling (i.e., participants can easily share the study with friends and
acquaintances on social media, thereby promoting further participation) (119), the ability to obtain a heterogeneous sample (e.g. geographically diverse) (116;120), and access to hard to reach or ‘hidden’ populations (e.g. carers, those involved in illicit behaviors) (116).

A variety of online recruitment strategies have been implemented that include paid advertising through social media websites, posting in online forums/message boards, and posting on social media websites such as Facebook (e.g. creating a Facebook group) and Twitter (e.g. sending out study-related tweets) (116). Online recruitment has been used in the context of numerous study designs including feasibility studies (121), pilot studies (122), observational research (123), longitudinal cohort studies (124), and randomized controlled trials (RCTs) (125;126).

However, challenges do exist when recruiting online. Firstly, while convenience sampling can be facilitated by online recruitment, this avenue is limited when the goal is to obtain a random sample. Secondly, while online methods can help optimize the recruitment of participants into a study, survey completion rates as well as retention rates remain relatively low (Mean=52.2%; Range: 5.8% to 77%) (120) especially when compared to other methods of contact such as email, phone and text messages (81%) (127). Finally, online recruitment is enhanced by both online and offline “word of mouth” referrals, suggesting that researchers’ must build rapport with participants to enhance recruitment and retention (128). When participants are anonymous due to the online nature of recruitment or are hard-to-reach due to stigma, building rapport can present a unique challenge.

3.2.3 The potential of Twitter for participant recruitment

While the use and benefit of Facebook for research recruitment has been described in the literature (111;118;127;129), our knowledge of Twitter is limited. This absence of evidence
about Twitter may explain why its utility as a research tool is not apparent to health researchers (115). This lack of ‘observability’ (i.e. the degree to which the value of an innovation is apparent to others) is a common problem in the broader body of online health research as few articles report detailed descriptions of their recruitment strategies (116). To date, only one study has provided an in-depth description of the process and outcome of recruiting through Twitter (130).

As mentioned earlier, when a study uses convenience sampling, the potential to “snowball sample” through online recruitment is high. This is especially true of Twitter as it operates in a manner that is particularly conducive to snowball sampling. “Retweeting” (i.e. sharing another user’s tweet) is a core activity within Twitter (119;130). By retweeting, users share the study information with their followers. In this way, the single tweet by a researcher has the potential to be amplified and seen by thousands of potential participants. Moreover, Twitter users can “mention” specific users in their retweets – making the sharing of information more tailored (119). In one study where the Twitter recruitment process was described extensively, 21% of the tweets that the researchers posted were retweeted by other users, aiding them in recruiting 5.3 times more than the target sample size (130). This begins to demonstrate the important and useful role that Twitter can play in optimizing the recruitment process. While this foundational study has begun to delineate the potential use and outcome of Twitter recruitment, much has yet to be explored.

### 3.2.4 The heterogeneity of participants recruited through Twitter

There has been some discussion in the literature about whether data collected through online recruitment is generalizable to the larger population (120;124). The representativeness of a sample recruited online is enhanced when the population is diverse in aspects such as demographics and geography (124). The majority of information about sample
representativeness is derived from studies that employed Facebook recruitment strategies. This body of evidence is mixed with some authors reporting negligible differences between samples recruited online compared to other means (131) and other authors pointing to significant differences in the socioeconomic status of samples recruited online versus through hospital (118).

This disagreement in the literature highlights two important considerations. Firstly, while social media may be a beneficial way to enhance research recruitment, traditional recruitment avenues (e.g. local healthcare organizations) should not be neglected (119). Secondly, it is important to continue investigating how participants recruited through social media may be similar or different from those recruited through traditional methods. Although some studies have begun to make such comparisons in the context of Facebook, our knowledge of these similarities and differences from a Twitter recruitment perspective remains limited.

First proposed by Everett Rogers, the Diffusion of Innovations Theory is frequently used to understand how innovations (typically technology-based) are adopted in different settings and at what rate (132). One aspect highlighted in this theory as affecting uptake of an innovation is its “observability”– ‘The degree to which the results of an innovation are visible to others’ (132).

Our present work contributes to increasing Twitter’s ‘observability” by evaluating Twitter as a recruitment strategy and communicating this to the larger research community (115). Specifically, within the context of a study on peer support exchange between family carers, we used Twitter as one method of recruiting participants. Our paper aims to outline our recruitment procedure and to answer the following questions: 1) Do carers recruited through Twitter differ demographically and in their Internet proficiency from carers recruited via other methods?; 2) What was the nature and extent of the study-related tweets that were posted?; and 3) What was the extent to which study-related tweets were shared by others?
3.3 Methods

3.3.1 Design
The main study used mixed method design to explore peer support exchange with a sample of adult children caring for aging parents. We administered both a web-based survey and conducted qualitative interviews with adult children carers (ACCs) to investigate their experiences with online versus in-person peer support. For the present paper, only the quantitative data was used to address the research questions.

3.3.2 Participants
We aimed to recruit 80 adult children carers who were engaged in online or in-person peer support activities. To be included in the study, participants had to be: 1) 18 years or older; 2) Able to read, write and speak English; 3) Assisting their parent with at least one activity once a week; 4) Engaged in some form of peer support (e.g. in-person support group, online forum) at least once a month; and 5) Providing care in Canada.

3.3.3 Convenience Sampling Strategies
Recruitment brochures were distributed through two national community care organizations as well as community support programs in four major Canadian cities (Toronto, Halifax, Calgary and Vancouver). We also posted study information in the discussion forum of a national hospice’s website and distributed study information through their virtual newsletter and social media channels. A Facebook page was also created and supplemented by paid advertisements.

3.3.4 Recruitment via Twitter
The first author (MBW) used her personal Twitter account for the recruitment process. In February 2014, MBW began sending tweets related to the study. All of the tweets included, at
minimum, the link to the study survey as well as information about the target population (e.g. adult children in Canada caring for a parent and are engaged in peer support). General recruitment tweets were sent out where a ‘call for participants’ was posted without targeting any specific users. These tweets typically included a request for a ‘retweet’ (RT) (Figure 3-1).

**Figure 3-1: Example of a general recruitment tweet**

![Example of a general recruitment tweet]

Additional tweets were sent by ‘mentioning’ relevant stakeholders who would be willing to “retweet” the study survey link (i.e. share the tweet with their own followers). In addition to caregiving- or health-focused users, influential users (e.g. media personalities, celebrities, political figures) as well as users with many followers were also asked to retweet the study survey link.

A range of “hashtags” were used during the recruitment process. A hashtag denotes a topic of interest and when clicked, retrieves all tweets that used the same hashtag. We used hashtags such as ‘#caregiving’, ‘#peersupport’, ‘#aging’ and ‘#elderly’ in order to increase the likelihood that a study-related tweet would be seen by users interested in these topics.

MBW also engaged with and reached out to a number of communities on Twitter that are defined by a certain hashtag. For example, #hcsmca (healthcare social media Canada) is a community of healthcare professionals, researchers, policy makers, patients, and carers that share information and engage with one another using the #hcsmca hashtag. Other communities that were tweeted at were #alzchat (Alzheimer chat) and #ElderCareChat.
3.3.5 Data Collection

To address our first research question, we compared carers recruited via Twitter with those recruited through other convenience sampling methods on the following characteristics: a) age; b) gender; c) ethnicity; d) province of residence; e) marital status; f) parenting status; g) number of dependents; h) primary daily activity; i) household income; j) highest level of education; k) caregiving duration; l) Internet proficiency; and m) frequency of Internet use.

To address our second and third research questions pertaining to the aggregation, extraction and analysis of study-related tweets, we used a third party application called Twitonomy (www.twitonomy.com). Twitonomy allows you to log in via your Twitter username where it then analyzes your account activity (e.g. number of tweets sent, average tweets per day, number of your tweets that were retweeted, hashtag use, mentions, and links shared) (See Figure 3-2 for sample output).

Figure 3-2: Twitonomy analytics sample output

It is important to note that Twitonomy analysis is limited to a user’s most recent 3200 tweets and 800 mentions. For this reason, we were only able to use Twitonomy to retrieve and
analyze tweets beginning April 1st, 2014. Recruitment however commenced on February 1st, 2014 and therefore a manual extraction and analysis of tweets for the months of February and March 2014 was conducted using the MBW’s Twitter archive (i.e. a history of all tweets from the account). Twitonomy is also limited to analyzing a user’s entire account and since MBW used her personal Twitter account (rather than creating a study-specific one); Twitonomy was not able to isolate the study-related tweets. In turn, Twitonomy facilitated the aggregation and extraction of tweets but this list was then manually reviewed by a volunteer reviewer to identify tweets that were relevant to the study. MBW then went through the list a second time to ensure that no relevant tweets were missed.

In addition to aggregating and extracting the tweets, Twitonomy provided information on how many times a specific tweet was retweeted (i.e. shared by other users). This captured the percentage of study tweets that other users shared with their own followers, thereby increasing the exposure of the original tweet. Although Twitonomy provided information about the number of times a specific tweet was retweeted, it did not indicate which users posted the retweet. Without information about the number of followers a user has, we were not able to calculate the reach of the tweets. In turn, this limited our ability to use Twitonomy to address our second research question pertaining to the overall reach of study-related tweets. We were partially able to investigate reach by selecting the top 10 most retweeted tweets and cross-referencing them with www.retweet.co.uk. This online application provides a list of all users that retweeted a specific tweet.

3.3.6 Data Analysis

To conduct the comparative analysis of carers recruited through Twitter vs. convenience sampling, we used IBM SPSS Statistics V. 23 (99) to calculate the means and frequencies for
each group independently and then we conducted a series of Mann-Whitney and chi-square tests to test for differences between groups. As this was a secondary analysis, the study was not powered to detect significant differences between groups. In turn, we also used the Z score from the Mann-Whitney tests and the chi-squared values to calculate estimated effect sizes (Pearson’s $r$) (133). Effect size estimates were interpreted based on Cohen’s pre-determined effect sizes (0.1 for a small effect size, 0.2 for a medium effect size and 0.5 for a large effect size) (134).

To describe the nature of tweets posted, we reviewed the study-related tweets aggregated by Twitonomy and classified them into one of 5 categories (Table 3-1). By using the list generated by www.retweet.co.uk, we were able to observe who retweeted each of the top 10 tweets, search for their followers and total this across all users in order to calculate the “reach potential” of each tweet (i.e. the potential number of users who may have been exposed to the original tweet as a result of the retweets).

**Table 3-1: Category and number of study-related tweets posted**

<table>
<thead>
<tr>
<th>Tweet Category</th>
<th>Description</th>
<th>Number of tweets</th>
</tr>
</thead>
<tbody>
<tr>
<td>General recruitment tweets</td>
<td>Tweets where MBW posted a call for participants along with the study survey link. These tweets show up in the news feed of anyone who follows MBW.</td>
<td>124</td>
</tr>
<tr>
<td>Mention tweets</td>
<td>Tweets where MBW ‘tagged’ (i.e. mentioned) another user (typically asking them to kindly retweet the study survey link and call for participants). Users receive a notification if they are tagged in a tweet. When a tweet begins with an “@user”, it does not show up in the news feed of those that follow MBW.</td>
<td>1275</td>
</tr>
<tr>
<td>Engagement tweets</td>
<td>Tweets where MBW interacted with other users for study-related purposes (e.g. answering questions, thanking them for their retweet).</td>
<td>285</td>
</tr>
<tr>
<td>Media-specific tweets</td>
<td>Tweets that were related to a nationally syndicated radio spot that was done to promote the study and recruitment (e.g. MBW tweeting about radio show times, answering questions about the radio spot).</td>
<td>31</td>
</tr>
<tr>
<td>Tweet Category</td>
<td>Description</td>
<td>Number of tweets</td>
</tr>
<tr>
<td>----------------------------------------</td>
<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td>------------------</td>
</tr>
<tr>
<td>Study tweets posted by other users*</td>
<td>“Quote tweets” by other users (where a new tweet was generated by the user but entailed them either directly quoting or modifying a tweet by MBW).</td>
<td>84</td>
</tr>
<tr>
<td>Tweets where other users used their own words to share study information.</td>
<td></td>
<td>41</td>
</tr>
</tbody>
</table>

* We were able to identify these tweets due to MBW being mentioned (i.e. ‘tagged’) in them. Tweets about the study where MBW was not mentioned were not retrievable.

3.4 Findings

During the recruitment period (February 1st to October 1st, 2014), a total of 71 carers were recruited. Of these, 27 (38%) indicated that they had heard about the study through Twitter. The remaining 44 (62%) heard about the study through word of mouth, other media (e.g. Facebook, LinkedIn, news organization), a health-related organization or local support group.

3.4.1 Carers recruited via Twitter vs. other convenience sampling methods

The average age of the carers recruited through Twitter was 48.8 (Range: 23-65) and 51.6 (Range: 22-64) for those recruited through other methods. Carers were predominantly female (Twitter: n=23 (85.2%); other: n=41 (93.2%)), Caucasian (Twitter: n=25 (92.6%); other: n=39 (88.6%)) and living in Ontario (Twitter: n=20 (74.1%); other: n=30 (68.2%)). Both caregiving groups had been providing an average of 55 months of care, with the majority indicating that they did not co-reside with their parent (Twitter: n=23 (85.2%); other: n=33 (75%)) (See Table 3-1 for complete characteristics of each group).

Table 3-2 provides a detailed summary of the results of the Mann-Whitney and Chi-Square tests and presents the effect size estimates for each analysis. Overall, no statistically
significant differences were observed between groups on any of the variables tested. The effect size estimates ranged from 0 to 0.22, with the majority of analyses generating an effect size of less than 0.155. In turn, the magnitude of the differences between groups is small and has little practical significance.

Table 3-2: Comparative Analysis & Results

<table>
<thead>
<tr>
<th></th>
<th>Twitter (n=27)</th>
<th>Other (n=44)</th>
<th>U or χ²</th>
<th>p-value</th>
<th>Effect size estimate (r)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Average age of carer in years (range)</strong></td>
<td></td>
<td></td>
<td>U=439.5</td>
<td>p=0.67</td>
<td>0.217</td>
</tr>
<tr>
<td></td>
<td>48.78 (23-65)</td>
<td>51.84 (22-64)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Gender Δ</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Male</td>
<td>4 (14.8%)</td>
<td>3 (6.8%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Female</td>
<td>23 (85.2%)</td>
<td>41 (93.2%)</td>
<td>p=0.415</td>
<td>0.13</td>
<td></td>
</tr>
<tr>
<td><strong>Primary ethnicity Δ</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>White</td>
<td>25 (92.6%)</td>
<td>39 (88.6%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Non-white</td>
<td>2 (7.4%)</td>
<td>5 (11.4%)</td>
<td>p=0.459</td>
<td>0.065</td>
<td></td>
</tr>
<tr>
<td><strong>Province of residence Δ</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ontario</td>
<td>20 (74.1%)</td>
<td>30 (68.2%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Other</td>
<td>7 (25.9%)</td>
<td>13 (29.5%)</td>
<td>χ²=0.279</td>
<td>p=0.597</td>
<td>0.063</td>
</tr>
<tr>
<td><strong>Marital Status Δ</strong></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Single</td>
<td>10 (37.0%)</td>
<td>10 (22.7%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married/Common law</td>
<td>17 (63.0%)</td>
<td>34 (77.3%)</td>
<td>χ²=1.693</td>
<td>p=0.193</td>
<td>0.154</td>
</tr>
<tr>
<td>Have children? (Parenting status)</td>
<td>Twitter (n=27)</td>
<td>Other (n=44)</td>
<td>$\chi^2$</td>
<td>p-value</td>
<td>Effect size estimate (r)</td>
</tr>
<tr>
<td>----------------------------------</td>
<td>----------------</td>
<td>--------------</td>
<td>----------</td>
<td>---------</td>
<td>-------------------------</td>
</tr>
<tr>
<td>Yes</td>
<td>10 (37.0%)</td>
<td>27 (61.4%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>No</td>
<td>16 (59.3%)</td>
<td>17 (38.6%)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Missing</td>
<td>1 (3.7%)</td>
<td>0</td>
<td>$\chi^2$=3.44</td>
<td>p=0.064</td>
<td>0.22</td>
</tr>
</tbody>
</table>

| Average number of children (range) | 2.22 (1-3) | 2.09 (1-4) | U=400 | p=0.192 | 0.155 |

<table>
<thead>
<tr>
<th>Primary daily activity</th>
<th>16 (59.3%)</th>
<th>25 (56.8%)</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Working for pay</td>
<td></td>
<td></td>
<td>$\chi^2$=0.041</td>
<td>p=0.840</td>
<td>0.024</td>
</tr>
<tr>
<td>Not working for pay</td>
<td>11 (40.7%)</td>
<td>19 (43.2%)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Yearly household income</th>
<th>Pass (treated as missing)</th>
<th>Less than $60,000</th>
<th>Greater than $60,000</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>7 (25.9%)</td>
<td>6 (22.2%)</td>
<td>14 (51.9%)</td>
<td>$\chi^2$=0.000</td>
<td>p=0.983</td>
<td>0</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Highest level of education</th>
<th>Completed less than university</th>
<th>Completed university (bachelor degree) or higher</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>11 (40.7%)</td>
<td>16 (59.3%)</td>
<td>$\chi^2$=0.5841</td>
<td>p=0.445</td>
<td>0.091</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Average caregiving duration in months</th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
</table>
### 3.4.2 Tweets posted

In total, 1715 study-related tweets were sent between February 1\textsuperscript{st} and October 1\textsuperscript{st}, 2014.

During this time, MBW’s Twitter followers grew from approximately 64 to 629. On average, study-related tweets were sent 7.09 times a day. The type and number of tweets posted can be found in Table 3-1.
3.4.3 Retweet Activity

As previously noted, we were unable to retrieve retweet statistics for the tweets sent between February 1st and March 31st, 2014. Therefore, the retweet statistics are limited to the period between April 1st and Oct 1st, 2014 (See Table 3-3).

Table 3-3: Retweet Activity

<table>
<thead>
<tr>
<th>Type of Tweet</th>
<th>Percentage retweeted</th>
<th>Total retweets</th>
<th>Most retweets of a single tweet</th>
</tr>
</thead>
<tbody>
<tr>
<td>General recruitment</td>
<td>67.2%</td>
<td>96</td>
<td>7</td>
</tr>
<tr>
<td>(n=64)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mention tweets</td>
<td>27.1%</td>
<td>336</td>
<td>6*</td>
</tr>
<tr>
<td>(n=742)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Engagement tweets</td>
<td>0</td>
<td>0</td>
<td>0</td>
</tr>
<tr>
<td>(n=68)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Media-specific tweets</td>
<td>35.5%</td>
<td>15</td>
<td>2</td>
</tr>
<tr>
<td>(n=31)</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Tweets by other users</td>
<td>52.65%</td>
<td>145</td>
<td>28**</td>
</tr>
<tr>
<td>(n=57)</td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

* Tweet mentioned a health quality council and a patient-led organization
** Tweet was posted by an influential municipal political figure

3.4.4 Reach of Tweets posted

We were able to analyze the top 10 most retweeted tweets to calculate the total reach of each. Each of the ‘mention tweets’ listed in Table 3-4 was retweeted by the user that was tagged in the original tweet.
Table 3-4: Top 10 most retweeted tweets

<table>
<thead>
<tr>
<th>Type of tweet</th>
<th>(1) General recruitment</th>
<th>(2) General recruitment</th>
<th>(3) General recruitment</th>
<th>(4) Mention tweet</th>
<th>(5) Mention tweet</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of retweets</td>
<td>9</td>
<td>7</td>
<td>6</td>
<td>6</td>
<td>6</td>
</tr>
<tr>
<td>Tweet reach</td>
<td>7,033</td>
<td>5,273</td>
<td>19,073</td>
<td>9,664</td>
<td>8,578</td>
</tr>
<tr>
<td>User(s) mentioned in the tweet</td>
<td>N/A</td>
<td>N/A</td>
<td>N/A</td>
<td>Provincial Professional Association</td>
<td>Provincial Health Quality Association and a National Patient-led Organization</td>
</tr>
<tr>
<td>Top tweeter</td>
<td>Individual in a managerial role at a research hospital</td>
<td>Department at a major research university</td>
<td>Individual who is a retired healthcare professional and family carer</td>
<td>The research division of a post-graduate healthcare professional college</td>
<td>A National Patient-led Organization</td>
</tr>
<tr>
<td>Percentage of tweet reach that top tweeter accounted for</td>
<td>46.77%</td>
<td>29.64%</td>
<td>35.85%</td>
<td>46.77%</td>
<td>77.82%</td>
</tr>
</tbody>
</table>
### Type of Tweet

<table>
<thead>
<tr>
<th>Type of Tweet</th>
<th>(6) Mention tweet</th>
<th>(7) Mention tweet</th>
<th>(8) Mention tweet</th>
<th>(9) Mention tweet</th>
<th>(10) Mention tweet</th>
</tr>
</thead>
<tbody>
<tr>
<td>Number of retweets</td>
<td>5</td>
<td>5</td>
<td>5</td>
<td>4</td>
<td>4</td>
</tr>
<tr>
<td>Tweet reach</td>
<td>62,144</td>
<td>40,908</td>
<td>14,330</td>
<td>23,977</td>
<td>21,153</td>
</tr>
<tr>
<td>User(s) mentioned in the tweet</td>
<td>Journalist for a large North American Financial News Website</td>
<td>Local TV Personality</td>
<td>A City Councilor</td>
<td>Local Science-Themed Attraction Centre</td>
<td>A City Planner</td>
</tr>
<tr>
<td>Top retweeter</td>
<td>Journalist for a large North American Financial News Website</td>
<td>Local TV Personality</td>
<td>A City Councilor</td>
<td>Local Science-Themed Attraction Centre</td>
<td>A City Planner</td>
</tr>
<tr>
<td>Percentage of tweet reach that top retweeter accounted for</td>
<td>80.34%</td>
<td>93.23%</td>
<td>85.35%</td>
<td>73.90%</td>
<td>92.91%</td>
</tr>
</tbody>
</table>

Note. All 10 tweets were unique and posted at different times

### 3.5 Discussion

This paper aimed to describe the use of Twitter to recruit family carers for a study on peer support exchange and to explore whether carers recruited through Twitter. Specifically, we explored whether carers recruited through Twitter differed demographically and in terms of Internet proficiency from carers recruited using other convenience sampling methods. We described the nature and extent of tweets posted as well as the extent to which these tweets were shared by others. Between February and October 2014, a total of 71 family carers were recruited to the study (27 through Twitter). No significant differences in the demographic characteristics and Internet proficiency existed between caregiving groups. In total, 1715 tweets were posted.
and included general recruitment, mention and engagement tweets. The largest percentage of retweets was observed in the general recruitment category. Analysis of the top 10 most retweeted tweets highlighted the large reach potential of a single tweet.

3.5.1 Comparability of sample recruited through Twitter
Participants recruited online have been shown to be demographically different from those recruited through traditional convenience sampling methods (126;135). In turn, this can limit the generalizability of studies that employ online recruitment strategies. We observed, however, that carers recruited through Twitter did not differ from those recruited through other methods on demographic variables or Internet proficiency. This may be because adult children carers are more homogenous than other study populations (e.g. smokers recruited for smoking-cessation studies). Although the studies that found significant between-group differences had larger sample sizes than we did (Gordon et al, 2006: n=2500; Graham et al, 2006: n=130,000), they did not report effect sizes and therefore we have little insight into the magnitude of the differences.

Conversely, our study found very small effect size estimates (predominantly r<0.155) for all comparisons. This suggests that even with a larger sample size, it is likely that no significant between-group differences would be detected. This is consistent with other research that suggests that web-based recruitment does not substantially alter a study’s generalizability (122). Since the majority of our knowledge about group differences comes from health studies that used Facebook to recruit, it will be important for future research to continue building on our findings by reporting on Twitter recruitment and evaluating how it may or may not impact the type of participants recruited into a study.
3.5.2 Twitter as a recruitment strategy

A key aspect that should inform one’s decision to use Twitter to recruit is the population of interest for the study. In the case of our study, our population was family carers who are recognized as a hard to reach population (136;137). Access to this population is diminished predominantly by the absence of a common recruitment location (i.e. carers provide care in numerous contexts – home, acute care, rehabilitation settings) and the nature of their role (i.e. carers are already busy, making them difficult to reach and invite into studies) (137). With hard to reach populations, literature has highly recommended the use of snowball sampling. Since acquaintances/peers already know and have contact with others who meet the study criteria, referral is facilitated by the trust that already exists in their relationship (Atkinson & Flint, 2001). Thus Twitter offers an innovative strategy for snowball recruitment.

As was demonstrated in our study, MBW’s followers grew from 64 to 629 during the recruitment period. This was largely because MBW not only tweeted about the study but also engaged with various users and participated in a number of tweetchats. This enhanced her visibility and reputability leading to greater opportunities for engagement, more followers, better study exposure and ultimately, successful use of Twitter to recruit participants. This underscores that there is a time commitment required to ensure the success of Twitter as a recruitment platform. As several authors have noted, the use of Twitter to recruit participants requires establishing rapport with your followers that extends beyond recruitment purposes alone (116;138;139). Firstly, it is important to have a known online presence and many followers (139). This is facilitated by a reciprocal exchange of information (138) on topics other than study recruitment in order to maintain interest and appeal to your followers beyond a one-way dissemination of recruitment-related information (139).
While MBW’s many followers and non-study engagement with other users aided in enhancing the Twitter recruitment, an important trade-off of using this approach was that it made it more challenging to extract and analyze tweets pertaining exclusively to the study. This is an important area for future consideration by researchers planning to engage in Twitter recruitment. One way that this issue can be addressed is for researchers—especially those that do not have an existing Twitter account or many followers—to create a Twitter account specifically for their research endeavors. This would allow them to analyze the entire account and as long as studies happen sequentially (rather than simultaneously), researchers can use date limitations to analyze the tweets pertaining to specific study. Another (and perhaps more practical solution) is to create a unique study hashtag that can be run through third-party analytical software. This would help to identify tweets that are pertinent to the study and would allow researchers to maintain or create a Twitter account that is used for both research and general scholarly activities. Since reciprocity (i.e. both sharing and responding to tweets posted on Twitter) is a key element that transforms Twitter from a simple information-sharing site to a social networking platform that supports connections and relationships, it is highly advised that researchers carefully consider the use of study-specific accounts versus unique hashtags and in either case, plan for the engagement needed for Twitter to be a successful recruitment tool.

3.6 Strengths and Limitations
This paper is among the first in the health sciences literature to provide a detailed report and analysis of using Twitter to recruit participants into a health study. A strength of our analysis was the manual selection of study-related tweets by two reviewers. This reduced the likelihood that a study-related tweet was not captured. Another strength of this paper was the comparison of carers recruited through Twitter versus other convenience sampling methods.
As this was a secondary research objective, we were only able to compare carers on available demographic and Internet proficiency characteristics. In turn, there may be additional data that would distinguish the two groups that we did not anticipate and examine (e.g. proficiency with and use of social media specifically). Another limitation was our restricted ability to extract and analyze study-related tweets using Twitonomy. While this limited our ability to analyze the total number of retweets and overall study reach, we were able to gain some insight into reach by examining the top 10 most retweeted tweets.

3.7 Conclusions
This paper described the use of Twitter to recruit family carers for a study on peer support and to explore whether carers recruited through Twitter differed from carers recruited using other methods. Carers recruited through Twitter did not differ demographically or in Internet proficiency from those recruited via other methods. Tweets sent included general recruitment tweets, mention tweets and engagement tweets, with general recruitment tweets receiving the largest percentage of retweets. Analysis of the top 10 tweets indicated that the reach of a single tweet can range from 5,273 to 62,144 users. While Twitter helped us recruit hard-to-reach carers, researchers should carefully consider Twitter’s utility for accessing other populations of interest and prepare to invest time into building rapport and analyzing the recruitment process. Findings suggest that samples recruited through Twitter can be considered comparable to those recruited through other methods of convenience sampling, pointing towards the potential for generalizability in future research. Overall, our study provides preliminary but positive support for the use of Twitter as a recruitment strategy.
Chapter 4

4 Adult Children Carers’ Experiences with Online and In-Person Peer Support

4.1.1 Introduction

As North America and Europe’s elderly population continues to grow (1;2), caring for an aging parent will increasingly become part of adult children’s lives (18). In the U.S. and Europe, 49% and 30% of all carers are adult children, respectively (19;20). In Canada, 62% of carers over 45 years old are adult children (4). The literature suggests that caregiving experiences differ according to the carer and care-recipient relationship (141). This underscores the importance of focusing on the specific and unique experiences of adult children carers (ACCs). With the aging of the population, parental care has become a normal part of the life course (142). However, complex and prolonged care provision to parents is often at odds with ACCs’ other age-normative responsibilities such as employment, social activities and commitments to their own spouse and children (24). In turn, the parent care role can act as an added stress that exacerbates health decline and the restrictions in social functioning and quality of life experienced by ACCs (21-24).

The different dimensions of the caregiving situation (e.g. situational, personal, behavioral) can overlap and impact carers’ health and well-being (143). Due to the stressful nature of the caregiving situation, this impact is often negative (143). These caregiving-related declines can be mediated by the presence of social support (i.e. informational, emotional, and instrumental (tangible) assistance) (28). Conversely, when social support isn’t available, carers may experience financial, physical and psychosocial costs (144). Carers’ perception of social support (i.e. their appraisal that support from others is valuable and available when needed) is especially important as it has a stronger association with physical and mental health than actual support received (33-35). Qualitative investigation within this realm can therefore play an
important role in expanding our understanding of carers’ perspectives on and experiences with social support.

Peers are a key source of social support for carers (41). Homophily theory suggests that when peers are experientially similar (e.g. share caregiving commonalities such as care recipient relationship or illness), a supportive relationship ensues out of mutual understanding and empathy (37;38). When carers are similar to their peers, there is a greater chance that the support they receive from peers will match their actual needs (141). Support from peers can decrease isolation, buffer stress, and increase carers’ self-efficacy (50;145;146). Several studies have explored the delivery of supportive interventions using various modalities. Peer support interventions have typically been delivered as in-person group sessions that are offered by community or healthcare organizations (147) or through telephone support programs (148;149). Due to geographic and time constraints, however, many carers are turning to the Internet for this type of support (63).

Healthcare interventions are increasingly being delivered online due to the Internet’s unique ability to reach a large number of people in a cost-effective and convenient manner (64). These features have simultaneously promoted the development and widespread use of online social support groups (65). For tech-savvy ACCs (i.e. those who regularly use cell phones and have high-speed Internet in their homes (66)), the flexibility of accessing peer support from anywhere and at any time can be especially beneficial given their busy schedules. Early comparisons between online and in-person communication, however, argued that online interaction lacked the relational and identity cues (e.g. tone of voice, physical appearance, body language) associated with in-person communication. Therefore it was thought that online communication only permitted impersonal and inferior support relationship (67;150). In light of this position, a great deal of recent literature has focused on investigating web-based support
interventions for carers and showing that it is a feasible and valuable modality for intervention delivery and support exchange (151). Analyses of online carer discussion forums indicate that asynchronous Internet interaction can address carers’ inability to attend in-person support groups (68;69). Online interventions have also been shown to positively improve carers’ health and well-being (70;71).

As has been pointed out by Colvin et al (2004), the literature’s focus on evaluating online interventions and analyzing the content of online communication has led to an underrepresentation of carers’ personal reflections on using this modality for peer support exchange. While Colvin et al.’s (2004) study on carers’ perspectives of the unique advantages/disadvantages of online social support provides important qualitative insight to address this issue, its focus on the online experience alone underscores an additional limitation in the existing literature. To date, studies have largely investigated online and in-person carer peer support in isolation of one another. This approach affords a detailed focus on each modality and provides valuable insights into their unique aspects—e.g. the benefits of peer-led vs. professional-led in-person support groups (41) or the effectiveness of Internet interventions tailored to carers’ worksite or home setting (70;72). However, we only gain a partial understanding of how carers engage in and experience peer support across modalities.

Non-caregiving communication literature cautions against the view that online interaction exists separately from (rather than being integrated with) other day-to-day forms of communication (152;153). In light of this, the Internet should be considered one of many modalities that are used to achieve social and cultural goals as well as maintain relationships (73;74). Our study adopted this perspective and aimed to explore ACCs’ experiences with online and in-person peer support exchange while caring for an elderly parent. Specifically, we aimed to
answer two questions: 1) How do ACCs use online and in-person modalities to obtain support? 2) What type of support is exchanged within each modality?

4.2 Methods

4.2.1 Research Design
The data for this paper was derived from a larger mixed method study. For the qualitative portion of the study, we employed a descriptive approach. Qualitative description entails a concise and descriptively rich analysis that remains true to the data. In this way, it is less interpretative than other qualitative traditions and produces a “data-near” report (154). This method of qualitative inquiry produces an account of the data that is easily interpreted by practitioners, thereby making the findings meaningful to these key stakeholders and potentially applicable to care situations (81).

Qualitative description borrows from phenomenology and grounded theory in so far as it uses an iterative data collection and analysis process and allows for a theoretical frame to guide the design of a study and the analysis of findings (154). However, unlike research using grounded theory, we did not aim to use the experiences of individuals to build a theory or conceptual model (84). Additionally, we did not conduct a study applying phenomenology because we did not aim to construct a prototype of “lived experiences” across ACCs (84). Rather, we aimed to describe the range and type of experiences that ACCs had with interacting with peers either online or in person.

4.2.2 Participants
Participants were eligible for this study if they were (a) centrally involved in providing and/or coordinating care for their parent (i.e., aiding with one or more activities of daily living (ADLs) at least once a week) (e.g. ADL: dressing, bathing; IADL: managing finances, grocery
shopping); (b) English-speaking, (c) 18 years of age or older, (d) assisting their parent in Canada, and (e) in contact (either online or in person) with someone who is also caring for a family member. We used purposive sampling—specifically maximum variation sampling—to seek heterogeneity in interaction modality (i.e. online vs. in person), relationship to the care-recipient (i.e. daughter vs. son) and gender of the care-recipient (i.e. mother vs. father) (91). We recruited participants until theme saturation was reached (i.e., no new ideas were uncovered). On the basis of previous qualitative studies, we chose a projected sample size of 10–20 ACCs (88;155).

4.2.3 Recruitment

Several strategies were employed to recruit carers. Recruitment brochures were distributed to four community-based carer support groups in four major Canadian cities (Toronto, Halifax, Calgary and Vancouver). Liaisons at each support group provided carers with the brochure, which had information about the study and the survey web link. Additionally, recruitment brochures were distributed to two national community care organizations and a number of illness-specific organizations across the country. We also posted study information in the discussion forum of a national hospice’s website and the organization also distributed study information through their virtual newsletter and social media channels. A Facebook page was also created and paid Facebook advertisements were posted for a 2-month period.

The primary investigator (MBW) also used her Twitter account to “Tweet” the link to the study survey along with relevant hashtags (e.g. #carer, #caregiving, #research). The study survey link was also “tweeted” at relevant users (e.g. organizations or community managers) who may “retweet” the link to their own followers. (Details of this Twitter recruitment strategy were outlined in Chapter 3).
4.2.4 Procedure

Before we began recruitment, the research ethics boards of the University of Toronto reviewed and approved the study in 2013, in accordance with the Tri-Council Policy for Ethical Conduct Involving Humans. Carers who were interested in participating in the study first accessed the link to the online survey (hosted by FluidSurveys—a secure online survey application that is hosted in Canada). The first part of the survey screened carers for eligibility. Once carers met the inclusion/exclusion criteria, they were taken to the second page of the survey, which presented the consent form. The consent form included detail about the study as well as potential risks and benefits. Once carers provided their consent, they were directed to the full survey. Upon completing the online survey, carers were asked if they would like to participate in a qualitative telephone interview that would gain more in-depth insight into their online/in-person support experience with the randomly selected peer. If they said “yes”, they were prompted to provide their contact information for follow-up by the researchers. Researchers then called or emailed the participant and arranged for a time to conduct the telephone interview.

4.2.5 Data Collection

Each ACC participated in an in-depth semi-structured interview that was conducted over the phone. In each interview, we used open-ended questions to ask ACCs to describe: a) the caregiving situation (e.g. who are you caring for?; what type of assistance are you providing?); b) their engagement in peer-support activity broadly (e.g. which modalities do you use to interact with peers? What type of peer support do you receive/provide?; what has your overall experience with peer support been?); c) their experience interacting with a specific peer (e.g. Can you tell me about the relationship you have with this specific peer? Why do you interact with this peer online/in person?); and d) their experience with interacting online or in person with their peer (e.g. How (if at all) has interacting online/in person affected your relationship with this peer and
the support you exchange?). Each interview was transcribed verbatim by a professional transcriptionist. The authors then checked for accuracy by cross-referencing the transcripts with the original audio files. Identifying information was removed during transcription, analysis and manuscript preparation.

For descriptive purposes, we collected demographic information about the ACCs’ age, employment status, marital situation, and income level. The Carer Assistance Scale (CAS) also was included and consisted of 17 items asking carers to rate the amount of assistance they provide with a variety of ADLs and instrumental activities of daily living (IADLs) on a scale from 0 (“none”) to 6 (“a lot”(93)). Total scores range from 0 to 102, with higher scores indicating that more assistance is provided. The CAS has been shown to have good internal consistency (α = 0.87) and has been used in numerous caregiving studies (156;157). To capture the care-recipient’s functional abilities, carers were asked to complete the modified Barthel Index (94). This measure generates a score ranging from a minimum of 0 to a maximum of 20, where higher scores indicate more functional independence.

4.2.6 Data Analysis

Thematic content analysis was performed to identify themes from the ACCs’ narratives (102). Line-by-line coding informed the development of a coding framework which was applied to all transcripts (102;103). NVivo version 10 qualitative data analysis software (104) was used to facilitate the coding process. Analyses included comparing and contrasting the coded data and categorizing similar ideas. All authors participated in the final phase of the thematic analysis which entailed constant comparison until categories could be grouped into ‘themes’ that were distinct from one another (102;103).
4.3 Results
In total, 71 adult children carers (ACCs) completed the online survey, with 42 (59.1%) volunteering to participate in a telephone interview. We reached data saturation at 12 ACCs but interviewed an additional 3 participants in order to ensure that no new data was missed (i.e. over-saturated). In total, 15 ACCs participated in an interview and the themes below reflect their narratives. The telephone interviews lasted 52.2 minutes on average (Range: 26-77 minutes). The average age of ACCs was 51 years old (Range: 41-65 years old). Of the 15 ACCs, 9 (60%) indicated that they predominantly interacted with peers in person while 6 (40%) interacted predominantly online. Overall, most ACCs (73%) discussed using more than one communication modality. The majority of ACCs (80%) indicated that their peer was a family member, long-time friend or co-worker– suggesting that this population mobilizes their existing network for peer support. See Table 4-1 for all demographic details of qualitative and full study participants.

Table 4-1: Participant characteristics (qualitative and full study sample)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Full sample (n=71)</th>
<th>Qualitative sample (n=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age in years (SD)</td>
<td>51 (10.3)</td>
<td>51 (7.9)</td>
</tr>
<tr>
<td>Female</td>
<td>64 (90%)</td>
<td>10 (67%)</td>
</tr>
<tr>
<td>Province of residence</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ontario</td>
<td>51 (72%)</td>
<td>13 (87%)</td>
</tr>
<tr>
<td>Alberta</td>
<td>8 (11%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>Other</td>
<td>12 (17%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>White</td>
<td>66 (93%)</td>
<td>15 (100%)</td>
</tr>
<tr>
<td>Married/common law</td>
<td>45 (63%)</td>
<td>8 (53%)</td>
</tr>
<tr>
<td>Have children</td>
<td>38 (53%)</td>
<td>10 (67%)</td>
</tr>
<tr>
<td>Working for pay</td>
<td>42 (59%)</td>
<td>7 (47%)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than college</td>
<td>7 (10%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>Completed college</td>
<td>11 (16%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Some university</td>
<td>6 (8%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>University</td>
<td>30 (42%)</td>
<td>8 (53%)</td>
</tr>
<tr>
<td>Post-graduate studies</td>
<td>17 (24%)</td>
<td>5 (33%)</td>
</tr>
</tbody>
</table>
### Characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Full sample (n=71)</th>
<th>Qualitative sample (n=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Average yearly household income</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $30K</td>
<td>5 (7%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>$30-59,999</td>
<td>12 (17%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>$60-89,999</td>
<td>9 (11%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>$90K+</td>
<td>33 (45%)</td>
<td>9 (60%)</td>
</tr>
<tr>
<td>Missing</td>
<td>14 (20%)</td>
<td>3 (20%)</td>
</tr>
<tr>
<td>Mean duration of care in years (SD)</td>
<td>4.6 (4.6)</td>
<td>5 (6.1)</td>
</tr>
<tr>
<td>Previously provided care</td>
<td>30 (42%)</td>
<td>9 (60%)</td>
</tr>
<tr>
<td>Caring for mother</td>
<td>52 (73%)</td>
<td>11 (73%)</td>
</tr>
<tr>
<td>Mean age of parent (SD)</td>
<td>81 (9.8)</td>
<td>83 (10.6)</td>
</tr>
<tr>
<td>Care-recipient illness*</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stroke</td>
<td>9 (13%)</td>
<td>2 (13%)</td>
</tr>
<tr>
<td>Cancer</td>
<td>8 (11%)</td>
<td>3 (20%)</td>
</tr>
<tr>
<td>Dementia</td>
<td>25 (35%)</td>
<td>7 (47%)</td>
</tr>
<tr>
<td>Alzheimer’s Disease</td>
<td>9 (13%)</td>
<td>3 (20%)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>10 (14%)</td>
<td>5 (33%)</td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Heart Attack</td>
<td>5 (7%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>Pulmonary Disease</td>
<td>11 (15%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Liver Disease</td>
<td>1 (1%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Parkinson's Disease</td>
<td>5 (7%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>Aging-related</td>
<td>27 (38%)</td>
<td>8 (53%)</td>
</tr>
<tr>
<td>Other (e.g. mental health, organ failure, COPD)</td>
<td>33 (46%)</td>
<td>8 (53%)</td>
</tr>
</tbody>
</table>

*Participants could indicate that their parent suffered from multiple illnesses*

On average, ACCs had been providing 5 years of care. The average Carer Assistance Scale (CAS) score was 45.3 out of a possible 102 (Range: 16-83), indicating that carers were providing relatively low to moderate levels of care. The majority of ACCs were providing care to their mother (n=11) and only 5 were co-residing with their parent. All ACCs reported that their parent had multiple co-morbidities including dementia, diabetes, COPD, cancer and general aging-related limitations. The average Barthel Index score was 14.26 out of a possible 20 (Range: 7-20), indicating that the care-recipients were moderately functionally independent.

Our analysis led to the identification of two descriptive over-arching themes: 1) ACCs take a pragmatic approach to peer support exchange and 2) The nature of peer support that ACCs
receive transcends the interaction modality. The first theme captures how carers engage in peer support and is comprised of two sub-themes: a) ACCs utilize a blend of communication modalities to interact with peers; and b) ACCs’ relational (e.g. quality relationships) and practical needs (e.g. efficient communication) drive their valuation and use of online or in-person peer support. Our second theme suggests that regardless of whether ACCs interacted online or in person, the type of support they received (e.g. emotional, appraisal, informational) was consistent across interaction modalities.

4.3.1 Theme 1: ACCs take a pragmatic approach to peer support exchange
ACCs took a very pragmatic approach to peer support exchange in as far as they obtained the support they needed through “any means necessary”. While the study focused specifically on online and in-person communication, carers also discussed their supplemental use of telephone calls and text messages, highlighting their blended and pragmatic approach to peer interaction. Carers perceived each modality as having unique attributes and advantages. Based on these perceptions, carers chose the modality that best-addressed their ‘relational’ and ‘practical’ support needs. Carers’ ‘relational needs’ centered on wanting good quality relationships and valuable communication with theirs peers. Conversely, their ‘practical needs’ entailed wanting to maximize the efficiency and magnitude of their supportive exchanges (i.e. using minimal time for maximum support benefit). Overall, this theme highlights that ACCs’ peer support patterns are highly variable and that they use different strategies for different reasons.

4.3.1.1 Sub-theme (a): ACCs utilize a blend of communication modalities to interact with peers
A chief concern for many ACCs was the availability and possibility of using any given modality for supportive exchanges. Several carers discussed that having an in-person relationship with
their peer would be impossible due to geographic restrictions (i.e. peer did not live close enough for in-person interaction to take place). Some carers also noted that limitations in time prevented them from meeting with peers in person. One participant explained that despite having an in-person relationship with his peer initially, geographic time restrictions introduced a challenge to maintaining the in-person relationship:

CG07 (Male, 65 years old): “I think early in our friendship we were just more available to each other. Now I’m not available as much and she’s certainly not here in [major Canadian city] and so geographically, there’s a big change. The whole online world has become something that makes it easy to stay in touch with people you haven’t seen recently or aren’t geographically close to.”

Conversely, other carers described having many existing in-person relationships and interactions with their peers (e.g. working together; shared activities). Participants explained that this not only created an opportunity for in-person peer support exchange but often made it easier than alternative methods. One carer’s comment reflects this as he describes the ease with which he comes across peers in his daily routines:

CG08 (Female, 41 years old): “The interactions are mostly social. So it’s a few people that I actually work with. So it’s easy to connect with them at the workplace, whether that’s going for lunch or going for a coffee. One of my peers I see at the gym. So we’re more apt to kind of connect briefly there.”

While ACCs were prompted to reflect on their experiences with online and in-person interaction, as this was the focus of the study, they also discussed phone calls and text messages as additional ways of interacting with their peers. From a pragmatic perspective, carers seemed to use these modalities in combination with one another to facilitate their ability to interact with peers. The combination of modalities used was often dictated by whom the peer was, where they were located and the nature of the relationship with that person:

CG10 (Female, 52 years old): “Well, it could be just like chatting in a hallway kind of thing or sending emails. Sometimes it’s texting. Like meeting someone for tea or coffee. That kind of thing. Primarily... my sisters and I are texting or emailing when we’re
communicating a lot because we're all in different locations. Friends just contact me mostly by email or texting.’

CG13 (Male, 48 years old): ‘It's a mix. I mean my wife is a primary face-to-face. My other friends from way back are more phone discussions. So I’d say face time in terms of caregiving discussion is like 99.5% with my wife.’

Phone calls and texting were described as ways to both supplement and emulate online and in-person communication. Since participants could hear a peer’s voice over the phone, they frequently described phone calls as being similar to and interchangeable with in-person interaction:

CG01 (Male, 48 years old): ‘I like in-person interaction versus, for example, texting or emailing. It's the live voice. Like telephone is good too for me. Speaking to someone on a phone is good for me. But anything that isn't live voice, I don't really like for talking about caregiving or anything that really matters to me.’

CG13 (Male, 48 years old): ‘Oh, well, I don't interact with people online. I mean that's just not my thing. So I enjoy socializing in person. I don’t socialize in other ways, unless it's a phone call.’

This similarity between phone calls and in-person communication is also illustrated by ACCs’ use of phone calls to supplement in-person meetings. In some cases this was because phone calls were more convenient than in-person interaction and in other cases, as one carer describes, it was because phone calls allowed for lengthier conversations:

CG 13 (Male, 48 years old): ‘When I'm speaking to a friend of mine on the phone, it’s not such a big deal if you talk for like an hour and a half or something. But if you're talking to someone in your workplace, you're talking for the amount of time that is available, which is not an hour and a half. It's usually like a few minutes. And you're also influenced by who happens to walk in the room at any given time because we have an open format office.’

ACCs commented that texting was comparable to email communication and felt that it was a way to convey information quickly and to check in with peers:

CG10 (Female, 52 years old): ‘You know, I'm rushing either to work... or I'm on my way home on the subway. You know, things are quick. So it's just easy to send someone a quick message and give them a quick update that way.’
Other carers viewed email as a more time-intensive and in depth endeavor and used text messages as a similar but more efficient alternative:

*CG12* (Female, 44 years old): “Texts are great because it can be a quick check-in on the fly. But I don’t have the time right now to do an 8 paragraph long update to people as to where I’m at on email because I just don’t have the capacity in my day.”

4.3.1.2 Sub-theme (b): ACCs’ relational and practical needs drive their valuation and use of online or in-person peer support

ACCs discussed their experiences with the modality that they predominantly used to interact with peers (i.e. online or in person). ACCs’ use of a modality appeared to depend on how well it aligned with their relational and practical needs. Relational needs entailed building quality relationships with their peers and having meaningful interactions. These needs were often influenced by participants’ personality and their communication preferences. Carers’ practical needs entailed maximizing the quality of support as well as the efficiency with which it was received (e.g. minimal time consumption, conveniently fitting into their routines/schedules). Practical needs were often influenced by carers’ circumstances and in turn, the modality chosen was perceived as the most reasonable and appropriate to meet these needs.

*Relational Needs.* The ACCs who predominantly interacted with peers in person appeared to prioritize their relational needs. These carers explained that they had extroverted personalities and described themselves as being a “people-person”. They also valued visual and voice cues (e.g. tone, body language, facial expressions) when interacting with peers—aspects they felt were limited by online communication:

*CG02* (Female, 55 years old): “I find a lot of people who send text and emails, sometimes are coming across maybe not how they mean it to. It’s hard to get the tone.”

ACCs commented that face-to-face interaction promoted transparency and honesty as it was more difficult to “hide” or suppress something when there were visual and voice cues available. ACCs also described in-person communication as enabling intimate relationships that are
characterized by empathy and connectedness. One ACC’s comment reflected the fact these relational aspects of in-person communication positively contributed to his overall well-being:

\[CG05\ (Male, 54\ years\ old):\ “Face-to-face\ contact\ is\ always\ better\ than\ any\ other\ contact...it’s\ better\ for\ my\ mental\ well-being\ because\ my\ experience\ when\ I\ was\ in\ crisis\ was\ to\ hide\ and\ isolate\ myself...\ And\ part\ of\ my\ mental\ health\ and\ well-being\ is\ to\ make\ sure\ I\ continue\ to\ interact\ with\ people.”\]

In-person interaction also aligned with the way these ACCs preferred to communicate. One participant viewed himself as a “listener” more than a “talker” and felt that he could be more easily excluded from online conversations compared to in-person ones. A few other ACCs expressed a preference for talking about caregiving rather than writing messages online:

\[CG02\ (Female, 55\ years\ old):\ “The\ girlfriends\ that\ I\ talk\ about\ that\ are\ carers\ or\ were\ carers...I\ would\ not\ really\ talk\ to\ them\ about\ it\ [caregiving]\ online...\ I\ guess\ I’ve\ never\ been\ one\ who\ really\ likes\ to\ write.\ So\ I\ would\ rather\ talk.”\]

Although ACCs who interacted predominantly online did so mostly due to the modality’s alignment with their practical needs, several relational needs were also met. Several ACCs explained that by sending long ‘letters’ or quick updates via email, they were better-able to ‘keep in touch’ with their peers resulting in a greater sense of connectedness. A few carers also noted that the option of having private and anonymous communication online seemed to facilitate more self-disclosure and honesty about one’s circumstances. One carer explained why this was the case for her:

\[CG04\ (Female, 58\ years\ old):\ “When\ you\ begin\ a\ conversation\ with\ another\ carer,\ it\ becomes\ very\ intimate,\ very\ quickly\ online.\ Because\ you’re\ not\ giving\ your\ full\ name\ and\ you’re\ asking\ very\ personal\ questions...so\ I\ can\ kind\ of\ be\ incognito\ and\ ask\ for\ advice\ on\ touchy,\ personal\ issues.”\]

Practical Needs. As discussed, ACCs’ use of in-person interaction was mostly characterized by its fit with their relational needs. However, some practical needs were also discussed. ACCs explained that it was important for there to be dedicated time and attention for peer support exchange. In person, the ACCs felt that they and their peers were more available to
each other and that it reduced the potential for distractions. ACCs also explained that in-person interaction permitted immediate responses to their comments and questions, which one ACC described as imperative for addressing her support needs at any given time:

*CG14 (Female, 62 years old):* “I’m talking about the immediacy of the response. Because I usually need to talk to somebody about something now. And by the time I hear from somebody on an email or they phone me back, I’ve moved on to some other issue.”

For ACCs who predominantly interacted with peers online, practical needs largely motivated their use of the online modality. For ACCs that could not feasibly interact with peers in person, the most practical aspect of online communication was that it had the ability to overcome geographic restrictions and permit peer support relationships in the first place:

*CG04 (Female, 58 years old):* “With her specifically [peer], she lives very far away and she doesn’t leave home ever. So the Internet and being online has given us an opportunity to have a relationship because otherwise we wouldn’t have a relationship.”

ACCs also wanted to be able to “reach” a greater number of peers in an efficient way, which was facilitated by online interaction. ACCs explained that because Facebook messages, Twitter ‘tweets’ and blog posts could be seen and responded to by a large audience, this expanded and amplified their support network. One ACC explained how she was better able to keep in touch with a number of peers globally through her blog:

*CG03 (Female, 49 years old):* “My parents got sick in 2006...I don’t know if Facebook existed then, but I wasn’t on it anyway if it did and Twitter didn’t exist then. Blogging was the first thing. So it was the blog, it was people. I have friends around the world that would check in.”

While ACCs who interacted with peers predominantly in person explained that they were deterred from online communication because of the perceived lack of privacy, ACCs who actually interacted online had the opposite opinion. These ACCs valued the practical ability to have a private Facebook group or to send a private ‘direct message’ on Twitter that other people
could not see. One ACC’s comment reflects how and why she uses private communication on Facebook:

CG09 (Female, 38 years old): “It depends on what the subject is [referring to caregiving issues]. Sometimes it’s with direct messaging on Facebook so that not everybody sees it. I have done a couple of secret groups on Facebook that are carer groups where people can put their own stuff, typically where their family can’t find it. So that if they do need to vent, it’s not spread around Facebook”

All of the ACCs who interacted online discussed the practical need for peer support exchange to be timely and convenient. ACCs felt that interacting online provided them with immediate contact and responses from peers, which was beneficial when information needs were imminent. One of the main conveniences of online communication was that it was readily available to the ACCs wherever they were and whenever they needed it. Compared to in-person interaction, ACCs felt that they didn’t have to carve out specific time for online peer support exchange. This idea of online support being at one’s “finger tips” was captured by two ACCs:

CG08 (Female, 41 years old): “I can fit it into whenever I need to use it. I don’t have to go out to do it. I have the technology in my pocket to be able to connect to a whole bunch of people that have way more experience than what I do.”

CG09 (Female, 38 years old): “We [carer & peer] remain relatively respectful of each other’s time but know that at any given point if one or the other needs to say ‘This is what’s going on right now, I need help’, it’s a couple of clicks away.”

4.3.2 Theme 2: The nature of peer support that ACCs receive transcends the interaction modality.

ACCs’ narratives suggested that regardless of whether they were interacting online or in person, the type of support they received was consistent across modalities. ACCs described receiving emotional, informational and appraisal support from their peers. Most frequently, ACCs received emotional support from their interactions with peers. Emotional support was described variably by ACCs but often entailed “just talking” to their peer. By talking to peers about
caregiving, ACCs felt that they were not alone in their experiences. As described by two ACCs, sharing and connecting with peers reduced feelings of isolation:

*Online CG10 (Female, 52 years old):* “It makes me feel good that I have someone who is very understanding and that I’m in her thoughts. It’s good because I don’t feel alone … You just feel like you have company even when the person isn’t right beside you.”

*In person CG15 (Female, 50 years old):* “It was really helpful to talk to other people who had their parents in that same facility. It was very helpful just to know that I was not the only one… it was good to have those very few one off conversations with others who could really relate to how difficult I was finding it.”

ACCs benefited greatly from their peer’s empathy and understanding as it allowed them to ‘blow off some steam’ and ‘vent’. As two ACCs explained, talking to a peer who understood their circumstances helped them cope with and move on from frustrating experiences:

*Online CG04 (Female, 58 years old):* “And a couple of times when it got really, really rough for me, it [talking to peers] did help me. There were times when I just needed to vent or times that I just needed to cry. And just having that shoulder to cry on or that ear that just let me vent allowed me to kind of centre myself again.”

*In person CG08 (Female, 41 years old):* “I think the support has been really good just as far as all you need really is an understanding ear or someone who can see your perspective. That way it doesn’t just look like a vent and that you’re just hating on the world, but that this is building up, you’ve had a number of bad days with the person you’re caring for and you just need to kind of talk through it and relieve the situation and carry on.”

ACCs also described their peer support exchanges as extending beyond the care situation. ACCs mentioned that in many cases, the type of emotional support they received from their peers was simply ‘friendship’. As two ACCs explained, this meant that interactions with peers didn’t necessarily have to be centered on caregiving alone or at all for them to value the support:

*Online CG06 (Male, 52 years old):* “Either way it’s just a casual friendship, an expression of interest in how each other is doing in life in general and in terms of our role as carer.”

*In person CG15 (Female, 50 years old):* “I’m not seeking out support around my caregiving in my friendship… it’s sort of beside the point. [The peer support] is a by-product of my friendship.”
The more ‘social’ aspects of peer support exchange were an important reminder of life ‘beyond caregiving’. ACCs explained that caregiving can be a time-consuming and all-encompassing experience, making it easy to forget about other aspects of one’s life and personality. When this happened, peers played an important role in helping ACCs to ‘take a break’ from caregiving. This often entailed humorous exchanges or participating in non-caregiving activities. Two ACCs reflected on how their peers helped them “escape”:

Online CG11 (Female, 63 years old): “We had a good laugh on Facebook just yesterday...2 of the 3 [peers] responded very humorously. And so you take that and it gives you a little energy boost to keep on truckin’.”

In person CG08 (Female, 41 years old): “It’s good to have a night out. It's good to have the sanity check and to have some laughs over how life is and how crazy things can be.”

In addition to emotional support, ACCs received appraisal support from their peers. This type of support was characterized by peers evaluating or commenting on something the ACC had done for their parent. ACCs explained that this made them feel supported in their decision-making and provided a sounding board or a way to be ‘on the same page’ as other carers. Two ACCs described how receiving confirmation and encouragement from their peers affirmed that they were not only doing the best they could but that they were making good choices:

Online CG04 (Female, 58 years old): “If I’ve done something, if I’ve made a choice, a decision at the moment and I’ve just thought ‘Oh my gosh, I’m not sure if that’s the right thing that I did’....I’ll often say [to peers online], ‘This is what I said to my mom or this is what I did’....and I was looking for a lot of support. And a lot of people said ‘No, you did the right thing’. So I get that kind of support online.”

In person CG14 (Female, 62 years old): “I have to say; when I talk to her it’s like a reset button. You know, it just knocks me a little bit to remind me that I’m doing the best I can do and that thinking otherwise isn’t helping me or the situation any.”

Informational support was also frequently received by ACCs from their peers. Informational support was comprised of online caregiving information or advice based on a peer’s personal experience. ACCs explained that some peers shared educational resources or
caregiving agency information that the ACC may not have known about or not had time to seek out themselves. This information was found mostly online even if ACCs indicated they interacted with their peers predominantly in person. In other cases, ACCs interacted with and learned from their peers’ personal experiences. This information was typically centered on the parent’s illness (e.g. symptoms to look out for, treatment options, care facility options) and management of the caregiving role. Two ACCs described receiving either online information or personal recommendations from a peer:

**Online CG06 (Male, 52 years old):** “[Peer provides] go-to resources or how to access anything... [for my] parent's needs or a service that's out there in the community that can be provided.”

**In person CG08 (Female, 41 years old):** “She [peer] also provides good insight and different approaches, and keeps me in check as well... It's good to get a different perspective.”

Some ACCs described temporal aspect to the informational support they received. These ACCs explained that although the information they received from peers was not always directly applicable to their present circumstances, it provided them with insight into what they could expect in the future. Two ACCs described how they sought or received information from peers about care transitions that their parent may undergo in the future:

**Online CG06 (Male, 52 years old):** “I seek support online because I often have questions about the difference between a seniors residence and assisted living? You know, what's the cost of assisted living? And what are people's experiences with their parents in assisted living? Because that's the type of transitioning we're looking at doing now. And so I seek information and support.”

**In person CG01 (Male, 48 years old):** “One person was talking about her experiences with her mother in a private long term care home and I went away from that thinking...these are things to watch for in case for some reason it turns out that my father should go into a private care home.”
4.4 Discussion

Our study aimed to investigate adult children carers’ (ACCs) experiences with online and in-person peer support. Fifteen ACCs participated in a qualitative interview and from their narratives we identified two themes. Overall, ACCs’ engagement in peer support was highly variable with different needs and perceptions influencing their use of various communication modalities. The first theme reflected ACCs’ pragmatic approach to peer support, characterized by their blended use of communication modalities to meet relational and practical support needs. The second theme highlighted the fact that ACCs received emotional, informational and appraisal support from their peers regardless of the modality they used to interact.

By exploring peer support activity outside of the intervention context, our study was able to shed light on the way that ACCs naturally engage in peer support across communication modalities. In accordance with communication theory, our findings suggest that the online realm is only one of many modalities that carers use to achieve their support goals and to maintain relationships with peers (73;74). The efficacy of this constellated approach to peer support is highlighted by the consistent receipt of emotional, informational, and appraisal support across modalities. That is, ACCs’ pragmatic (i.e. “whatever works”) use of various modalities seemed to successfully provide them with the support they required. This highlights the need to reconsider the online/in-person dichotomy in the delivery of carer support generally and peer support specifically.

Non-caregiving literature has begun to argue that individuals are able to easily intertwine online and offline activities and that the two cannot be separated (158). In turn, the ‘cyberspace-physical space’ comparison is like a ‘false dichotomy’ as many relationships operate in both dimensions (159). These principles were reflected in our findings in two ways. Firstly, ACCs were able to effectively use various modalities to address different relational and support needs.
Secondly, ACCs used different and multiple modalities to maintain relationships with different peers. Given that this sub-population of carers has become adept at seamlessly using different modes of communication for different supportive purposes, it will be important for future interventions to provide peer support in a similarly pragmatic and flexible way.

Support programs that are broad in nature and deliver the same type of support in the same way to all carers have been shown to have little impact on carer ability and well-being (160). Comparatively, those that are more individualized and consist of multiple components improve the quality of support delivered to carers and reduce carer burden (160-162). While existing research has emphasized the value of interventions that deliver multiple support components to carers in a dynamic and interactive way (163;164), little research has focused on implementing and evaluating peer support interventions that integrate various interaction modalities. This is especially relevant given that peer support interventions have traditionally been delivered as in-person support groups, an approach that has been found to be less beneficial for ACCs compared to spousal carers (165;166). ACCs’ unique personalities and circumstances are reflected in their complex needs and multi-faceted support-seeking approach. Rather than evaluating online and offline interventions in isolation of one another or comparing their outcomes, future research would benefit from continuing to explore carers’ combined use of these modalities and determining how they can be effectively integrated into interventions to optimize peer support delivery.

4.5 Strengths and Limitations

To the best of our knowledge, this is the first study to investigate carers’ engagement in and benefit from peer support outside of the intervention context. In turn, our findings provide novel insight for support delivery as they reflect carers’ innate and preferred support patterns. One
limitation of our study became apparent after data analysis, namely that ACCs use other modalities for peer support that we did not capture by limiting our focus to “online” and “in-person” domains. Future research would benefit from exploring carers’ use of other modalities (e.g. phone calls, text messaging) and how they augment or compliment the in-person and online peer support investigated in our study. Carers in our study were well-educated and had relatively high annual household incomes. In turn, the peer support experiences and needs of ACC populations with lower socioeconomic status may differ from those discussed in our study. Finally, the ACCs who participated in our study were required to be interacting with a caregiving peer. Consequently, our study did not capture the experiences and potentially different needs of ACCs who lack or choose not to interact with peers.

4.6 Conclusion

Our study explored adult children carers’ (ACCs) experiences with online and in-person peer support. ACCs’ engagement in peer support was highly variable with different needs and perceptions influencing their use of various communication modalities. ACCs approached peer support pragmatically and used a blend of communication modalities to meet their relational and practical needs. Overall, ACCs received the same type of support from peers (i.e. emotional, informational, appraisal) regardless of the modality of interaction. Given that ACCs use a number of communication modalities for different purposes, our findings suggest that it is not constructive to dichotomize support delivery as either ‘online’ or ‘in-person’. ACCs’ approach to peer support was variable and complex, highlighting the need for future interventions to be tailored not only to this population’s multi-faceted support needs but also their pragmatic and flexible support-seeking style.
Chapter 5

5 How does peer similarity influence adult children carers’ perceptions of support from peers? A mixed method study

Citation: Wasilewski, MB; Stinson, JN; Webster, F; Cameron, JI. How does peer similarity affect adult children carers’ perceptions of support from peers? A mixed method study. Journal of Mixed Methods Research (Under Review, July 2016).
5.1 Abstract

**Background:** Adult children carers (ACCs) are increasingly caring for elderly parents. Social support from similar peers can offset caregiving-related health declines. Outside of the carer intervention context, little is known about peer similarity’s influence on perceived support.

**Methods:** Mixed methods using web surveys and qualitative interviews.

**Findings:** With 71 ACCs, peer similarity was positively and significantly associated with perceived support (Beta=0.469, p<0.0005) and explained 18.5% additional variance. Narratives suggested the most important aspect of similarity was shared caregiving experience as it optimized support received and enhanced relationship quality.

**Conclusion:** Peer similarity importantly contributes to ACCs’ perceptions of support. A comprehensive understanding of ‘shared caregiving experience’ is needed to inform peer-matching interventions. Peer similarity’s influence on relationship quality should be explored.
5.2 Introduction

As North America and Europe’s elderly population continues to grow (1;2), caring for an aging parent will increasingly become a likely and normative part of adult children’s lives (18). In the U.S. and Europe, 49% and 30% of all carers are adult children, respectively (19;20). In Canada, 62% of carers over 45 years old are adult children (4). The literature suggests that the caregiving experience differs according to the relationship of the carer to the care-recipient (141), underscoring the importance of focusing on the specific and unique experiences of adult children carers (ACCs). More so than in the past, ACCs are providing increasing amounts of complex care to one or both parents over a longer period of time (18). These characteristics of the care situation are often at odds with ACCs’ other age-normative responsibilities such as employment, social activities and commitments to their own spouse and children (24). In turn, the parent care role can act as an added stress that exacerbates health declines and the restrictions in social functioning and quality of life experienced by ACCs (21-24).

The impact of caregiving on ACCs’ health and well-being can be mediated by social support (i.e. informational, emotional, and tangible assistance) (28). The presence of social support can mitigate caregiving-related declines in health and well-being but its absence can lead to financial, physical and psychosocial costs for carers (144). Carers’ perception of social support (i.e. their appraisal that support from others is valuable and available when needed) is especially important as it has a stronger association with physical and mental health than actual support received (33-35).

Peers are a key source of social support for carers (36). The Interactional-Cognitive Model of Social Support (ICMSS) highlights the importance of individuals’ perceptions of support from specific peers (48). The ICMSS considers both the social behaviors entailed in person-to-person interaction as well as the cognitive processes that underlie individuals’
appraisals of the interaction (48). According to the ICMSS, there are three important domains that overlap and allow us to understand the social support process: 1) situational (e.g. caregiving situation, peer support context); 2) intrapersonal (e.g. personality, coping, mastery); and 3) interpersonal (e.g. frequency of contact with specific peers, duration of the relationship, peer similarity, perceived support) (48). Since the ICMSS does not focus on an individuals’ total network size or objective measures of support received, it is well suited to guide studies focused on individual peer support relationships.

Homophily theory suggests that when peers are experientially similar (e.g. share caregiving commonalities such as relationship to the care recipient or care-recipient illness), a supportive relationship ensues out of mutual understanding and empathy (37;38). Peer similarity can be understood in terms of four important domains: 1) structural similarity (e.g. demographic similarity); 2) appraisal similarity (e.g. perceiving/assessing situations similarly); 3) psychological similarity (e.g. similar emotional and mental states); and 4) experiential similarity (e.g. current caregiving experience) (37). Similarity across these domains has the potential to optimize the match between a carer’s socioemotional needs and the support they actually receive (141). In turn, support from similar peers can decrease isolation, buffer stress, and increase carers’ self-efficacy (50;145;146).

Although existing studies have begun to investigate the notion of peer similarity in the caregiving context, the majority of this literature has been interventional research. Interventions that match caregiving peers based on similarities have found only modest improvements in carer health and social outcomes post-intervention (37;45). One study that implemented a ‘befriending’ intervention (i.e. peer mentorship and support) found that it led to minimal improvements in carers’ quality of life and no cost-saving (46). In their systematic review of ‘mentoring schemes’ for dementia carers, Smith & Greenwood (2014) found that while peer-
matching lacked efficacy as an intervention, the qualitative findings highlighted the value that

carers placed on experiential similarity. In turn, they concluded that the importance of

experiential similarity and need for matching criteria required further investigation (47).

Similarly, Pillemer & Suitor (2002) discussed that future research needed to reconcile the lack of
efficacy of their peer matching intervention with the body of literature suggesting that peer
similarity promotes well-being in naturally-occurring networks.

To address these recommendations, this study endeavored to explore the concept of peer
similarity and its influence on carers’ perceptions of support outside of the intervention context.

By focusing on non-interventional support, our study allowed carers to reflect on their naturally-
occurring interactions with peers utilizing a number of modalities (i.e. in person, telephone,
online, etc). This allowed the findings to transcend the modality-specific effects reported in
existing peer support interventions (e.g. efficacy in phone-based support programs but not face-to-face ones) (147). The complexity of relationships and the discrepancy in qualitative and
quantitative findings within the existing literature suggested that a mixed method approach was
needed. As a result, we employed a mixed method design to explore the objective relationship
between peer similarity and perceived support as well as ACCs’ subjective perspectives on peer
similarity, its various aspects, and how it might influence support received from peers.

5.3 Research questions

5.3.1 Quantitative

1. Is an ACC’s perceived similarity with a peer associated with their perceptions of support

   from that peer?

2. Does peer similarity contribute to variation in perceived support above and beyond other

   variables?
Hypothesis 1: Higher perceptions of similarity to a peer will be positively associated with higher ratings of perceived support.

Hypothesis 2: Peer similarity will contribute to the variance in perceived support above and beyond other variables (i.e. covariates).

5.3.2 Qualitative
How do ACCs describe similarities/dissimilarities with their peers? How do they perceive similarity with peers to relate to their supportive exchanges?

5.4 Methods
5.4.1 Design
We employed a convergent parallel mixed method design, characterized by the concurrent collection of quantitative and qualitative data, separate analysis of the data sets and integration of the findings at the level of comparison and interpretation (75). The quantitative strand of the study employed a cross-sectional survey design and the qualitative strand of the study took a qualitative descriptive approach (81). Qualitative description is a branch of naturalistic inquiry that is not highly interpretative and remains data-near, making the findings easily understood and applied by policy makers and healthcare professionals (81).

5.4.2 Participants
The target sample for the study was carers who were engaged in peer support activities. To be included in the study, participants had to be: 1) 18 years or older; 2) able to read, write and speak English; 3) assisting their parent with at least one activity of daily living (ADL) (e.g. bathing, dressing) or instrumental activity of daily living (IADL) (e.g. managing finances, grocery shopping) at least once per week; 4) interacting with another carer; and 5) providing care in Canada.
5.4.3 Quantitative and Qualitative Sample Sizes

A rule-of-thumb for calculating the sample size for a regression analysis is 10 participants per independent variable (85). However, Harrell (2011) has suggested that 8 to 9 participants per independent variable is sufficient for a regression analysis as long as the variables are well-justified by the literature (86). Given that our selection of variables was theoretically rooted, we felt confident that 80 participants (8 participants x 10 independent variables) would give our analysis sufficient statistical power.

Participants who completed the online survey were given an opportunity to volunteer for an in-depth qualitative interview. We then purposively sampled a subset of carers with the goal of having equal carer and care-recipient gender representation (i.e. daughters/sons, mothers/fathers) and modality representation (i.e. online and in person) (88). Analysis occurred concurrently with interviewing and we closed recruitment once “theme saturation” was reached (i.e., no new ideas were uncovered in participant interviews) (84;88).

5.4.4 Recruitment

A multi-faceted recruitment strategy that employed online and in person recruitment was used. Recruitment brochures with the study survey link were distributed to four community-based carer support groups in four major Canadian cities (Toronto, Halifax, Calgary and Vancouver) as well as two national community-care organizations. The study was also advertised through Canadian Virtual Hospice (CVH) (a national online education and support website for patients and carers) and two online carer communities. Each of these groups shared study information through their social media channels, electronic newsletters and online discussion forums. The primary investigator (MBW) also used her Twitter account to “Tweet” the link to the survey (Details of this Twitter recruitment strategy are described in Chapter 6) and created a Facebook page and paid Facebook advertisements were posted for a 2 month period.
5.4.5 Procedure
Once carers were directed to the study survey (hosted on FluidSurveys™, a secure online application local to Canada), they were asked to answer the eligibility questions and eligible carers were then taken to the consent form. If they consented to participate, they were taken to the full survey. This survey asked participants to respond to the questionnaires based on their relationship with a specific peer. To do this, carers were asked to list up to 5 peers they interact with. The survey program then randomly selected one of these peers as the focus of the survey (and subsequently for part of the interview). Random selection of a peer was implemented to mitigate the potential bias associated with carers selecting a peer themselves (e.g. carers may have automatically selected their closest or most supportive peer, limiting data heterogeneity). Once they completed the survey, participants had the option of volunteering to be contacted for a qualitative telephone interview.

5.4.6 Quantitative Data Collection
Participants were asked to complete a battery of questionnaires. The constructs that were measured and their associated measurement instruments are described below and organized according to the domains outlined by the Interactional-Cognitive Model of Social Support (48). These measures have been previously used and validated with similar populations (See Appendix E).

5.4.6.1 Situational Factors
Demographics
For descriptive purposes, a demographic questionnaire was administered (e.g. age, gender, caregiving context, etc).
Caregiving assistance provided

The 17-item Carer Assistance Scale (CAS) (93) asked carers to rate the amount of aid they provide with a variety of activities of daily living (ADL) and instrumental activities of daily living (IADL) on a scale from 0 (none) to 6 (a lot). Scores ranged from 0 to 102, where higher scores indicated carers provided more assistance.

Care-recipient (parent) dependency

The 10-item modified Barthel Index (94) assesses the degree of care-recipient independence by asking whether they are independent, moderately dependant or fully dependant in completing a combination of ADLs and IADLs. Scores ranged from 0 to 20, where higher scores indicated more functional independence.

Geographic Distance

Participants were first asked if they knew how far they lived from their peer. If ‘yes’, they were asked to indicate if they lived in the same country, province, city and neighbourhood. Higher scores indicated more proximity between peers.

5.4.6.2 Intrapersonal Factors

Coping ability

The 28-item Brief Coping Orientations to Problems Experienced (COPE) Inventory (95) captures various emotion- and problem-oriented coping strategies. Participants are asked to rate how often they use various coping methods on a scale of 1 (I haven’t been doing this at all) to 4 (I’ve been doing this a lot). Two subscales capture problem-based and emotion-based coping strategies. Scores for the problem-based coping sub-scale ranged from 6 to 24 and from 22 to 88 for the emotion-based coping sub-scale, where higher scores indicated more use of that coping style.
**Mastery**

The 7-item Pearlin Mastery Scale (51) captures individuals’ beliefs about the extent to which they are able to control or influence their life chances and outcomes. Participants were asked to indicate how much they agree with seven statements on a scale of 1 (strongly disagree) to 4 (strongly agree). Scores ranged from 7 to 28, where higher scores indicated higher levels of mastery.

**Extraversion**

The 4-item Extraversion measure (58) captures the aspect of individuals’ personality characterized by sociability, talkativeness, assertiveness and excitability. Participants were asked to indicate how much they agree with four statements on a scale of 1 (strongly agree) to 7 (strongly disagree). Scores ranged from 4 to 28, where higher scores indicated that individuals were more extraverted.

**Self-disclosure**

The 3-item Self-disclosure measure captures how likely the participant is to disclose intimate details about themselves (58). This measure asked participants to imagine that they are talking to someone face-to-face when answering 3 questions. Scores ranged from 3 to 21, where higher scores indicated higher levels of self-disclosure.

5.4.6.3 Interpersonal Factors
Duration of the peer support relationship

Duration of the peer support relationship was captured by asking participants to indicate the year they started interacting with their peer. This was then subtracted from 2014 (year in which participants completed the survey) to compute the duration of the relationship.

Frequency of contact between peers

Frequency of contact between peers was captured on a 6-point Likert scale item that asked participants to indicate how often they interacted with their caregiving peers (0= Less than once a month, 1= once a month, 2= a few times a month, 3= once a week, 4= a few times a week, 5= every day). Higher scores indicated greater frequency of contact between peers.

Peer Similarity

The 6-item Peer Similarity questionnaire asked participants to rate their overall similarity to a peer as well as their similarity in terms of values, personality, mood, worries and hobbies (1= Similar to 9= dissimilar) (96). While this is one of few validated questionnaires intended to capture peer similarity, we felt that other relevant domains of similarity were not included. In turn, four questions were added to capture demographic similarity, emotional/psychological similarity, and appraisal similarity as recommended by Sabir et al (2003): 1) This peer is similar/dissimilar to me demographically (e.g. age, gender, marital status); 2) This peer is similar to me in their feelings of self-worth and self-value; 3) This peer is similar to me in identifying positive aspects of caregiving (e.g. satisfaction with caregiving, benefits of caregiving); and 4) This peer is similar to me in finding caregiving to be stressful. One additional caregiving-specific question was also added: This peer is similar to me in terms of the caregiving situation (e.g. who they’re caring for, amount and type of care provided, how long they’ve been providing care).
Scores ranged from 11 to a maximum of 99, where higher scores indicated more similarity with the peer.

*Perceived support*

The support subscale of the Quality of Relationships Inventory (QRI) was used (97). The QRI is comprised of 25 items that capture support, depth and conflict in interpersonal relationships. The support subscale indicates the extent that an individual perceives another person to be a source of assistance across a variety of situations. This subscale consisted of 7 items that asked participants to rate (on a 4-point Likert scale) the extent to which they could turn to/rely on their peer for some sort of support (1=Not at all, 2=A little; 3=Quite a bit; 4=Very much). This subscale generated a total score that ranged from 7 to a maximum of 28, where higher scores indicated more perceived support.

5.4.7 Quantitative Data Analysis

For the quantitative data, means, frequencies and percentages were used to summarize the demographic characteristics of the sample population. To investigate the relationship between peer similarity and perceived support, we conducted a stepwise hierarchical multiple regression. We entered the covariates in step one and peer similarity in step two. All analyses were conducted using IBM SPSS Version 22 (99).

5.4.8 Qualitative Data Collection

Carers participated in one in-depth telephone interview. Each interview was guided by a set of open-ended questions that asked participants to describe: a) their caregiving situation (e.g. who they are caring for, what type of assistance they provide); b) their engagement in peer-support activity (e.g. types of peer support provided/received; how long they have been accessing peer support, overall experiences with peer support); c) their perceptions of similarity/dissimilarity to
the randomly selected peer (e.g. components of similarity, how they determine similarity); and d) the role that similarity (or dissimilarity) plays in their interactions (e.g. how do similarities/differences with peer influence that relationship, their interactions and the carer’s perceptions of support received). Throughout the course of the interview the “probing” method was used to encourage participants to discuss topics in greater detail – especially when the topics were of relevance to the research objective (98).

5.4.9 Qualitative Data Analysis
For the qualitative data, we followed the six steps of thematic analysis to identify themes from the ACCs’ narratives (102). This analysis began with a collaborative open coding of the transcripts that led to the development of an exhaustive coding scheme used to perform line-by-line coding of all transcripts. The constant comparative method was then used to identify distinct themes (88). NVivo version 10 (104) qualitative data analysis software was used to facilitate the coding process. Several individuals were involved in each stage of the analysis process, thereby reducing bias and enhancing the credibility of the findings (105).

5.4.10 Mixed Method Analysis
The ‘yield’ of a mixed method study (i.e. the novelty of the research that goes beyond the sum of its parts) is indicated by the degree of integration between the quantitative and qualitative data sets (106). To ensure high yield in the present study, ‘crystallization’ was employed. This process entailed looking at the convergence and divergence in the data sets through comparison and contrast in order to uncover new ideas that could not have been derived from the quantitative or qualitative data sets alone (107).
5.5 Findings

5.5.1 Participant Characteristics

The survey was accessed 563 times with 109 of visitors being eligible to participate in the study. In total, 71 (65%) adult children carers (ACCs) completed the web-based questionnaire, with 42 (59%) volunteering for a qualitative telephone interview (See Figure 5-1 for participant flow chart). The average age of ACCs was 51 years old (Range: 22-65; SD: 10.2), with the majority being female (90%). Since 16% of carers did not know how far away they lived from their peer, we excluded this variable from the regression analysis as it substantially reduced the sample size. Geographic distance was instead summarized descriptively, with the mean being 3.6 (SD: 1.0) indicating that on average, ACCs lived in the same province or city as their peer. See additional participant details in Table 5-1.
Figure 5-1: Participant Flow Chart

Visitors to survey
N= 563

Participants that completed eligibility criteria
N= 490

Incomplete eligibility criteria
N= 73

Ineligible participants
N= 381
Not over 18: n= 6
Not caring for parent: n=84
Not centrally involved in care: n=15
Not caring in Canada: n=18
Not in contact with a peer: n= 131
Consent explicitly denied (i.e. refused consent): n=5
Consent implicitly denied (i.e. no answer given): n=122

Eligible & consenting participants
N= 109

Incomplete surveys
N=38
Completed only eligibility criteria: n=8
Completed additional questions: n=30

Total number of complete surveys:
N= 71

Volunteered for qualitative interview
N=42

Participated in a qualitative interview
N=15
# Table 5-1: Participant Characteristics

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Carers</th>
<th>Non-completers (n=38)**</th>
<th>Qualitative Sample (n=15)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Mean age in years (SD)</td>
<td>51 (10.3)</td>
<td>51 (10.9)</td>
<td>51 (7.9)</td>
</tr>
<tr>
<td>Female</td>
<td>64 (90%)</td>
<td>22 (60%)</td>
<td>10 (67%)</td>
</tr>
<tr>
<td>Province of residence</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Ontario</td>
<td>51 (72%)</td>
<td>17 (45%)</td>
<td>13 (87%)</td>
</tr>
<tr>
<td>Alberta</td>
<td>8 (11%)</td>
<td>3 (8%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>Other</td>
<td>12 (17%)</td>
<td>7 (18%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>White</td>
<td>66 (93%)</td>
<td>22 (60%)</td>
<td>15 (100%)</td>
</tr>
<tr>
<td>Married/common law</td>
<td>45 (63%)</td>
<td>14 (37%)</td>
<td>8 (53%)</td>
</tr>
<tr>
<td>Have children</td>
<td>38 (53%)</td>
<td>13 (34%)</td>
<td>10 (67%)</td>
</tr>
<tr>
<td>Working for pay</td>
<td>42 (59%)</td>
<td>-</td>
<td>7 (47%)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than college</td>
<td>7 (10%)</td>
<td>2 (5%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>Completed college</td>
<td>11 (16%)</td>
<td>3 (8%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Some university</td>
<td>6 (8%)</td>
<td>0 (0%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>University</td>
<td>30 (42%)</td>
<td>0 (0%)</td>
<td>8 (53%)</td>
</tr>
<tr>
<td>Post-graduate studies</td>
<td>17 (24%)</td>
<td>4 (11%)</td>
<td>5 (33%)</td>
</tr>
<tr>
<td>Average yearly household income</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Less than $30K</td>
<td>5 (7%)</td>
<td>2 (5%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>$30-59,999</td>
<td>12 (17%)</td>
<td>3 (8%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>$60-89,999</td>
<td>9 (11%)</td>
<td>2 (5%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>$90K+</td>
<td>33 (45%)</td>
<td>1 (3%)</td>
<td>9 (60%)</td>
</tr>
<tr>
<td>Missing</td>
<td>14 (20%)</td>
<td>30 (79%)</td>
<td>3 (20%)</td>
</tr>
<tr>
<td>Mean duration of care in years (SD)</td>
<td>4.6 (4.6)</td>
<td>4.2 (3.1)</td>
<td>5 (6.1)</td>
</tr>
<tr>
<td>Previously provided care</td>
<td>30 (42%)</td>
<td>-</td>
<td>9 (60%)</td>
</tr>
<tr>
<td>Caring for mother</td>
<td>52 (73%)</td>
<td>2 (5%)</td>
<td>11 (73%)</td>
</tr>
<tr>
<td>Mean age of parent (SD)</td>
<td>81 (9.8)</td>
<td>79 (11.3)</td>
<td>83 (10.6)</td>
</tr>
<tr>
<td>Care-recipient illness*</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Stroke</td>
<td>9 (13%)</td>
<td>1 (3%)</td>
<td>2 (13%)</td>
</tr>
<tr>
<td>Cancer</td>
<td>8 (11%)</td>
<td>1 (3%)</td>
<td>3 (20%)</td>
</tr>
<tr>
<td>Dementia</td>
<td>25 (35%)</td>
<td>2 (5%)</td>
<td>7 (47%)</td>
</tr>
<tr>
<td>Alzheimer’s Disease</td>
<td>9 (13%)</td>
<td>0 (0%)</td>
<td>3 (20%)</td>
</tr>
<tr>
<td>Diabetes</td>
<td>10 (14%)</td>
<td>2 (5%)</td>
<td>5 (33%)</td>
</tr>
<tr>
<td>Multiple Sclerosis</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Heart Attack</td>
<td>5 (7%)</td>
<td>0 (0%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>Pulmonary Disease</td>
<td>11 (15%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Liver Disease</td>
<td>1 (1%)</td>
<td>0 (0%)</td>
<td>0 (0%)</td>
</tr>
<tr>
<td>Parkinson's Disease</td>
<td>5 (7%)</td>
<td>0 (0%)</td>
<td>1 (7%)</td>
</tr>
<tr>
<td>Characteristics</td>
<td>Full study (n=71)</td>
<td>Non-completers (n=38)**</td>
<td>Qualitative Sample (n=15)</td>
</tr>
<tr>
<td>---------------------------------------</td>
<td>-------------------</td>
<td>-------------------------</td>
<td>---------------------------</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Aging-related</td>
<td>27 (38%)</td>
<td>3 (8%)</td>
<td>8 (53%)</td>
</tr>
<tr>
<td>Other (e.g. mental health, organ failure, COPD)</td>
<td>33 (46%)</td>
<td>1 (3%)</td>
<td>8 (53%)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Mean Peer Similarity Score (SD)</td>
<td>69.7 (17.5)</td>
<td>-</td>
<td>70.7 (18.2)</td>
</tr>
<tr>
<td>Mean Perceived Support Score (SD)</td>
<td>22.4 (5.6)</td>
<td>-</td>
<td>22.3 (5.9)</td>
</tr>
</tbody>
</table>

* ACCs could indicate that the care-recipient had more than one illness and therefore total percentage does not add up to 100
** Non-completers were those who did not complete any of the outcome or covariate measures
Of the 38 non-completers, 9 (23%) did not answer any questions beyond the eligibility criteria and response rates for remaining questions varied (n=0 to 28)

### 5.5.2 Hierarchical Multiple Regression: Perceived Support

A hierarchical multiple regression was performed to predict perceived support from the covariates alone and then with the addition of peer similarity in the model (Table 5-2). The model including frequency of contact, duration of the relationship, self-disclosure, extraversion, problem-/emotion-based coping, amount of care provided, care-recipient’s functional independence to predict perceived support (Model 1) was statistically significant, $R^2=0.310$, $F(9,59)=2.949$, $p=0.006$; adj. $R^2=0.205$. The addition of peer similarity to the model (Model 2) led to a statistically significant increase in $R^2$ of 0.185, $F(1,58)=5.681$, $p<0.0005$. This indicates that the inclusion of peer similarity in the model increased the variance explained by 18.5%. Model 2 was statistically significant, $R^2=0.495$, $F(10,58)=5.681$, $p<0.0005$; adj. $R^2=0.408$. 
Table 5-2: Summary of hierarchical regression analysis for variables predicting perceived support

<table>
<thead>
<tr>
<th>Variable</th>
<th>Model 1</th>
<th></th>
<th></th>
<th>Model 2</th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td>B</td>
<td>Beta</td>
<td>Std. Error</td>
<td>B</td>
<td>Beta</td>
<td>Std. Error</td>
</tr>
<tr>
<td>Intercept</td>
<td>12.257</td>
<td>5.870</td>
<td>-0.008</td>
<td>4.810</td>
<td>5.319</td>
<td></td>
</tr>
<tr>
<td>Amount of care provided (CAS)</td>
<td>0.021</td>
<td>0.073</td>
<td>0.040</td>
<td>-0.027</td>
<td>0.035</td>
<td></td>
</tr>
<tr>
<td>Care-recipient functional independence (Barthel)</td>
<td>0.101</td>
<td>0.100</td>
<td>0.128</td>
<td>-0.024</td>
<td>0.114</td>
<td></td>
</tr>
<tr>
<td>Problem-based Coping</td>
<td>0.079</td>
<td>0.080</td>
<td>0.122</td>
<td>-0.024</td>
<td>0.105</td>
<td></td>
</tr>
<tr>
<td>Emotion-based Coping</td>
<td>-0.033</td>
<td>-0.073</td>
<td>0.063</td>
<td>-0.025</td>
<td>0.054</td>
<td></td>
</tr>
<tr>
<td>Self-Disclosure</td>
<td>-0.25</td>
<td>-0.26</td>
<td>0.108</td>
<td>-0.077</td>
<td>0.094</td>
<td></td>
</tr>
<tr>
<td>Mastery</td>
<td>-0.09</td>
<td>-0.06</td>
<td>0.184</td>
<td>0.016</td>
<td>0.159</td>
<td></td>
</tr>
<tr>
<td>Extraversion</td>
<td>0.236</td>
<td>0.158</td>
<td>0.170</td>
<td>0.234</td>
<td>0.146</td>
<td></td>
</tr>
<tr>
<td>Duration of the Relationship</td>
<td>0.056</td>
<td>0.155</td>
<td>0.041</td>
<td>0.061</td>
<td>0.035</td>
<td></td>
</tr>
<tr>
<td>Frequency of Interaction</td>
<td>1.418*</td>
<td>0.413</td>
<td>0.412</td>
<td>1.002*</td>
<td>0.367</td>
<td></td>
</tr>
<tr>
<td>Peer Similarity</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>0.152**</td>
</tr>
</tbody>
</table>

| R²                                            | 0.310   |          | 0.495    |          |          |
| Adj. R²                                       | 0.205   |          | 0.408    |          |          |
| F                                             | 2.949*  |          | 5.681**  |          |          |
| ΔR²                                           | 0.310   |          | 0.185    |          |          |
| ΔF                                            | 2.949*  |          | 21.186** |          |          |

Note. N=69. *p<0.05, **p<0.0005; B= Unstandardized regression coefficient; Beta= Standardized coefficient
5.5.3 Qualitative Sample
In total, 15 ACCs participated in an interview and the themes below reflect their narratives. We reached data saturation at 12 ACCs but interviewed an additional 3 participants in order to ensure that no new data was missed (i.e. over-saturated). The telephone interviews lasted 52.2 minutes on average (Range: 26-77 minutes). The average age of ACCs was 51 years old (Range: 41-65 years old). Of the 15 ACCs, 4 were son carers. The majority of ACCs were providing care to their mother (n=11) and only 5 were co-residing with their parent. For the most part, ACCs’ peers were family members, friends or co-workers, highlighting that this population mobilizes their existing network for peer support (See Table 5-1 for additional participant characteristics).

5.5.4 Qualitative Findings
One overarching theme was identified and captured the fact that ACCs considered “shared caregiving experience” to be the most important aspect of peer similarity. The relevance of ‘shared caregiving experience’ to ACCs’ peer support engagement was underscored by the fact that it strengthened ACCs’ relationship with their peers and optimized the support they received from peers.

5.5.4.1 Overriding Theme: Shared caregiving experience is the most important aspect of similarity between caregiving peers
The predominant theme in the data was that shared caregiving experience was the single most important aspect of similarity between ACCs and their peers. Although ACCs discussed other aspects of similarity/dissimilarity and how they influenced their support relationships, no aspect was described in as much depth and detail as shared caregiving experience. Shared caregiving experience included caring for an elderly parent, caring for the same illness population and being at a similar point along the caregiving trajectory. All ACCs agreed that similarities in caregiving experience were vital to a beneficial peer support relationship (e.g. valuable support, good
quality relations). However, other aspects of similarity (e.g. demographics, personality) were described variably and less consistently in terms of their importance and influence on ACCs’ interactions with peers.

Similarity in terms of demographics (e.g. age) and personality were not always viewed as necessary for a high-quality peer support relationship. In fact, a few ACCs commented that interacting with a peer who was different with respect to demographics or personality allowed them to get a ‘different perspective’ on things and to ‘think outside the box’. In this way, the ACCs didn’t feel that demographic or personality differences hindered the ability of a peer to relate to their circumstances. Few ACCs discussed similarity in values and life outlook. Shared values primarily related to a shared sense of responsibility to one’s friends and family while shared life outlook captured similarity in priorities, attitude and perspective. ACCs felt that they were closer to peers with whom they shared values and life outlook and that this was often the basis for their ‘friendship’. One ACC’s comment reflects how shared values—in this case, sense of responsibility—can play an important role in supportive exchanges with peers:

CG02 (Female, 55 years): “She has the same feeling of responsibility [and that’s] definitely helpful because if I ask her to do something, she knows that I’m asking because I need her. And so in that way, it’s good.”

Overall, ACCs’ narratives centered largely on similarities with their peers in terms of the caregiving situation (i.e. shared caregiving experience). Their comments indicated that shared caregiving experience not only influenced the support they received from their peers but also impacted the relationship they had with them.
5.5.4.1.1 Shared caregiving experience strengthens ACCs’ relationships with their peers

ACCs felt that without shared caregiving experience, a connection and relationship with their peers would not exist. This was highlighted by ACCs’ comments that shared caregiving experience was the thing that brought them together:

CG04 (Female, 58 years): “I truly do think it’s our experience, the fact of our life experience having been the same. Like it’s a shared experience. It’s not our personalities that brought us together….our shared experiences are caregiving experiences.”

CG13 (Male, 48 years): “I find that the similarity or dissimilarity in our personalities is not really the bonding agent. The bonding agent when discussing is the caregiving aspect of it.”

Shared caregiving experiences not only underlay peer support relationships but also strengthened them. ACCs’ narratives pointed to three main aspects of the peer support relationship that were positively influenced by shared caregiving experience: closeness, breadth and reciprocity. Closeness pertained to the intimacy between ACCs and their peers; breadth entailed the range and depth of topics discussed/experiences shared; and reciprocity related to the mutual exchange of support.

Many carers described their relationship with peers as being ‘close’. The intimacy entailed in these relationships was underscored by participants describing them as ‘friendships’. In most cases, it was implied by ACCs that shared experience allowed the relationship to extend beyond a purely support-based one into the realm of ‘friendship’. However, one ACC’s experience explicitly highlights this notion. This ACC attended a peer support group where he lacked similarities in caregiving experience with the other members of the group. In turn, he felt that those individuals could not effectively relate to his circumstances. His comment reflects that if those peers had been better-able to put themselves in his shoes, they could have:

CG01 (Male, 48 years): “...understood where I’m coming from and what kind of person I am. So it would be more of a friendship, I think.”
Several carers agreed that the shared caregiving experiences broadened their relationship with peers. This was reflected in the wider range and detail of topics discussed. One participant that had a pre-caregiving relationship with his peer felt that caregiving added a new dimension to their relationship and allowed it to grow. Other carers commented on how shared caregiving experiences allowed for candidness in a relationship. As reflected in one ACC’s comment, this sometimes meant being able to share even the unsavory details of one’s caregiving experience:

*CG04 (Female, 58 years): “We tell each other the gory details of our caregiving responsibilities regularly.”*

In addition to the relationship being broadened through discussions of caregiving, carers felt more comfortable discussing a wider range of topics with peers who shared the caregiving experience. Participants’ comments indicated that this was because shared caregiving experience gave way to a certain level of trust and ease with peers, leading them to feel comfortable enough to ‘talk about anything’. As one ACC explained, trusting her peer and being able to discuss any range of things made that interaction smoother and more beneficial:

*CG09 (Female, 38 years): “I think it makes it easier to actually exchange information and to talk about things because I don’t feel like I have to guard myself, my words and my feelings when I’m saying it. I can just say it. It certainly makes it easier to ask for assistance and it also makes it easier to get it all out, to have that open conversation.”*

Comments from a few ACCs reflected their belief that the peer support relationship was a two-way exchange where they not only received support but reciprocated it as well. Having similarities with peers in terms of the caregiving experience allowed for mutual understanding and respect for one another. This was important since ACCs felt more guarded and less likely to exchange with a peer if a mutual sense of respect did not exist. The shared experience of caregiving was also discussed as the basis for the reciprocal sharing of advice and
encouragement. This is reflected in one ACCs’ comment about his interaction with people in her
network who are also carers:

   CG06 (Male, 52 years): “[Caregiving] is one big thing that we have in common. So we just commiserate with each other and again, offer each other free advice or some mutual respect and encouragement.”

Although some differences in the caregiving experience did not restrict the reciprocity of the
peer support relationships (e.g. duration or extent of care provided), a few ACCs felt that mutual
support exchange was limited by their peer being at a different point along the caregiving
trajectory. One ACC’s comment highlights that when carers are not at the same stage of
caregiving, support tends to flow in one direction (i.e. either given or received but not both):

   CG13 (Male, 48 years): “You know, I'm talking to friends who are a similar age as me but their parents are a decade younger. I offer more like advance signs and things they should look for, or things they should consider.”

5.5.4.1.2 Shared caregiving experience optimizes the support received from peers

Participants predominantly discussed shared caregiving experience as enhancing the emotional,
informational and appraisal support they received from their peers. Shared caregiving
experience allowed peers to better-relate to the ACCs’ circumstances, which led to empathy and
understanding. This emotional support was described by one ACC as making her “feel better”
because she just needed a ‘listening ear’:

   G08 (Female, 41 years): “I think the support has been really good just as far as all you need really is an understanding ear or someone who can see your perspective...so it doesn’t just look like a vent and you’re just hating on the world...you just need to talk through it and relieve the situation and carry on.”

Participants also explained that shared caregiving experience made them feel like they belonged
to a community, which reduced isolation. One ACC commented on this sense of community:
CG10 (Female, 52 years): “It’s a life stage; all of my friends have elderly parents...so we’re all kind of in this together. You know, a lot of us are going through similar situations”

Although carers didn’t speak extensively about how shared caregiving experience influenced the appraisal support they receive from peers (i.e. evaluative feedback), a few did comment that it was important for their peer to be caring for a parent with a similar illness. One ACC explained that each illness has its own unique set of conditions and when peers can relate to those, they are a better source of ‘validation’:

CG08 (Female, 41 years): “I just have a couple of girlfriends that are dealing with parents that actually have the same diagnosis of Alzheimer’s and dementia [and that’s important] because it validates and there’s a better understanding of what you’re going through. If I was talking to someone let’s say who had a parent with cancer, that’s a different set of circumstances that I can’t relate to or that they might not be able to relate to what I’m dealing with.”

Finally, participants felt that shared caregiving experience led to timely and relevant informational support from their peers. ACCs spoke about the importance of their peer caring for a parent (rather than another family member), their parents being approximately the same age and having the same illness as the ACC’s. These aspects were particularly important because ACCs perceived information based on care for a different illness group or a different family member as less relevant to addressing their needs. One ACC’s comment about her experience with a peer support group captures this:

CG08 (Female, 41 years): “I was sitting in a group with 2 or 3 other people that were probably in their 60s and 70s dealing with this [caregiving] with their spouse. So that doesn’t help me because I need to connect with people my own age that are dealing with parents. Because it’s not just the illness that I’m dealing with...It’s also kind of the administrative portion of caregiving that’s fallen on my shoulders because I am an only child.”

5.5.5 Mixed Method Insights
(1) More similarity to a peer is associated with higher perceived support

The integration of the quantitative and qualitative findings enhanced our understanding of the way that peer similarity and perceived support interact in the context of ACCs’ supportive exchanges with peers. The quantitative and qualitative data both suggested that being more similar to a peer was associated with perceiving them to be a greater source of support. Carers felt that similar peers could better-relate to their circumstances and provide timely and relevant support. This may explain why peer similarity was the most influential independent variable in the regression model (Beta=0.469) and accounted for an additional 18.5% of the variance in the hierarchical regression.

(2) Not all aspects of similarity equally contribute to perceptions of support

Although peer similarity had the highest Beta and was the only independent variable (in addition to frequency of contact) to significantly contribute to the regression model, the Beta was a modest 0.469. The 18.5% additional variance that peer similarity accounted for in the hierarchical regression can also be considered moderate at best. The qualitative findings may shed light on why—although significant—peer similarity did not contribute more strongly to the prediction of perceived support. ACCs’ comments suggested that while similarity with peers was important overall, not all aspects of similarity (as captured by the measurement instrument) are equally important. To ACCs, the most important aspect of similarity was shared caregiving experience because it fostered better understanding and more relevant support from peers. However, ‘experiential similarity’ was only one question on the peer similarity measure we used. The remaining questions pertained to structural, appraisal and psychological similarity—aspects not highly prioritized in ACCs narratives. This discrepancy highlights that the peer similarity measure may not have been robust enough in capturing the intricacies of ‘experiential similarity’ and the extent to which they may influence perceived support.
(3) Relationship quality influences the association between peer similarity and perceived support

In addition to peer similarity influencing perceived support, the qualitative data elucidated that peer similarity also impacts the nature of the peer support relationship. Specifically, more similarity with a peer helped to enhance the quality of the relationship—characterized by closeness and intimacy. The qualitative findings also suggested that these ‘high quality relationships’ may influence carers’ perceptions of support. Namely, ACCs trusted peers with whom they had good relationships and in turn placed more value on support received from them. While the quantitative analyses focused exclusively on the association between peer similarity and perceived support, the qualitative data began to elucidate that relationship quality may influence this association.

5.6 Discussion

This mixed method study aimed to explore the influence of peer similarity on adult children carers’ (ACCs) perceptions of peer support. In total, 71 ACCs completed the web-based questionnaire and 15 completed an in-depth qualitative interview. Peer similarity was positively and significantly associated with perceived support and explained variation in perceived support above and beyond other variables. ACCs narratives highlighted that while overall similarity with a peer was valuable, the most important aspect of similarity with a peer was shared caregiving experience. Having caregiving similarities with peers not only optimized the support received (i.e. made it more tailored and relevant) but also strengthened their relationship (i.e. increased closeness, breadth/depth, reciprocity). Support from relationships that were perceived as ‘good’ (i.e. characterized by closeness, breadth of topics discussed, and reciprocity) was especially valued.

Social comparison theory suggests that especially in times of uncertainty (e.g. illness and caregiving), individuals want to be in contact with others who are experientially similar in order
to evaluate their own abilities, opinions and emotions through comparison (167;168). This may explain why during ‘personal crisis’ (e.g. non-normative life changes such as caregiving), experiential similarity overrides other aspects that are typically of importance to relationship development (169). This was reflected in our finding that ‘shared caregiving experience’ was the most important aspect of peer similarity for ACCs–also echoing the literature suggesting that experiential similarity is the only influence on carers’ peer support exchanges and health outcomes (47). Current research suggests that because ‘experiential similarity’ is the only relevant aspect of similarity, ‘extensive matching criteria’ for peer support programming are not needed (37;47). While this may be true for demographics or personality, it is apparent from our study that ACCs naturally interact with peers with whom they share a range of caregiving similarities. This underscores that matching criteria centered on structural (e.g. demographics) and psychosocial domains (e.g. personality, values) may warrant less attention than matching criteria aimed at pairing peers based on specific caregiving similarities (e.g. relationship to care-recipient, illness population cared for).

Despite the demonstrated importance of ‘experiential similarity’, several studies focused on elder caregiving have taken a very one-dimensional approach to the concept. Aside from considerations of the illness population being cared for, these peer support studies have predominantly conceptualized ‘experiential similarity’ as two people sharing the status of ‘carer’ (37;170;171). Findings from our study suggest that ‘experiential similarity’ is multi-faceted and extends beyond simply sharing the caregiving role. ACCs in our study pointed towards important aspects of caregiving similarity such as being at the same point along the caregiving trajectory, caring for a parent and caring for the same illness. The peer similarity measure we used prioritized psychological similarity to a peer (e.g. personality, mood, values); and although we supplemented it with questions to capture additional domains of similarity outlined in Sabir et
al.’s (2003) caregiving study, it was not a comprehensive assessment of shared caregiving experience. In light of the prominent role that ‘experiential similarity’ plays in carer peer support, peer similarity measures employed in caregiving research may benefit from placing greater emphasis on capturing the multi-faceted aspects of the caregiving situation. This has the potential to help researchers understand the role and value of overall peer similarity compared to caregiving-specific similarity when designing and delivering support interventions.

A systematic review of peer mentor programs for dementia carers concluded that more information about experiential similarity’s influence on the peer support relationship is needed (47). Our study suggested that similarity with a caregiving peer optimizes the relationship itself and that ACCs especially value support from these peers. Specifically, shared caregiving experience brought peers closer, increased the breadth and depth of their interactions and enhanced reciprocity. These aspects are echoed in the notion of ‘tie strength’ which explains that a tie between two individuals (i.e. their bond) can be classified as ‘strong’ or ‘weak’ based on: 1) time spent in the relationship (e.g. duration and frequency of contact); 2) intimacy of the relationship (e.g. breadth of topics discussed); 3) intensity of the relationship (e.g. closeness); and 4) reciprocal services (e.g. supportive exchanges) (172). In non-caregiving contexts, more similarity between peers has been suggested to strengthen the ties they develop with one another (44). Social support from ‘strong ties’ has been linked to better mental health outcomes. Tie strength has yet to be investigated in the caregiving literature but may be an important area of research since these findings combined suggest that tie strength may moderate the effect that peer similarity has on perceived support.

5.7 Strengths and Limitations
To the best of our knowledge, this is the first study to take a mixed method approach to explore the relationship between peer similarity and perceived support amongst caregiving peers outside
of the intervention context. Our integration of both quantitative and qualitative data allowed us to not only report statistical relationships between the variables of interest but also to explain how and why these relationships may exist. One limitation of our study was that we did not achieve our a priori quantitative sample size of 80. It is also possible that we did not capture other variables that may impact perceived support and confound the influence of peer similarity (e.g. total network size). We also elected to exclude geographic distance as a variable in the regression due to low response rates, limiting our insight into how it may affect the model. Another limitation pertains to the relative homogeneity of our sample. Most ACCs were well-educated and had relatively high household incomes. In turn, our findings may not be transferable to carers of lower socioeconomic status.

5.8 Conclusion

This mixed method study aimed to explore the influence of peer similarity on adult children carers’ (ACCs) perceptions of peer support. Peer similarity was positively and significantly associated with perceived support and explained variation in perceived support above and beyond other variables. ACCs narratives highlighted that the most important aspect of similarity with a peer was shared caregiving experience. Overall, our study highlights that peer similarity—specifically shared caregiving experience—optimizes support from peers and improves the quality of their relations. In the future, studies should comprehensively capture the various aspects of caregiving similarity to inform peer-matching interventions. While the peer support relationship itself has not been the focus of much research, our study underscores that similarity with a peer may improve relationship quality and in turn, enhance support received.
Chapter 6

6 Summary, Integrated Discussion & Implications
6.1 Introduction

As the proportion of elders in the population rises globally and care continues to shift from institutional settings to the community, more and more family members will be relied upon to provide elders with day-to-day assistance. In the U.S. and Europe, 49% and 30% of the caregiving population is comprised of adult children, respectively. In Canada, 62% of carers over 45 years old are adult children (4;19). Given that the parent care role can conflict with other age-normative responsibilities (24), finding ways to support adult children carers (ACCs) is an important step in mitigating caregiving-related health declines. Social support is especially beneficial to ACCs as it can broaden their ability to manage their role and in turn, reduce the harm posed by caregiving-related stressors (31). Peers are a unique and important source of social support for family carers as their experiential similarity can allow a supportive relationship to ensue out of mutual understand, empathy and help (31;36;37).

Carers have typically sought peer support from in-person groups but due to geographic and time constraints, many carers are unable to meet with their peers in person and are consequently turning to the Internet for this support (63). This explains the rise in Internet-based interventions for carers and the abundant focus on comparing them to in person interventions (141). This however has led to an under-representation of carers’ personal and day-to-day experiences with peer support engagement across communication modalities. This limitation is also apparent in the body of literature exploring ‘peer similarity’ between carers. While the concept has begun to receive some attention, the literature has predominantly focused on interventions that ‘match’ carers with a similar peer (46;47). In turn, our understanding of peer similarity and the role it plays in carers’ supportive exchanges with peers is limited to the
interventional context. This is especially problematic given that intervention-based studies have found peer similarity to result in minimal improvements in objective measures of carer health and social outcomes yet qualitative data suggests that carers value and benefit from interaction with similar peers (47). This underscores the need to reconcile the lack of efficacy of ‘peer similarity’ in an interventional context with the literature suggesting that peer similarity promotes well-being in naturally occurring networks (38).

6.2 The Present Research

The goal of the present research was to measure outcomes and capture ACCs’ experiences with peer support in a non-interventional setting. This research also aimed to investigate ACCs’ relationships with specific peers in addition to their overall peer support experiences. Due to the challenges associated with traditional recruitment methods, Twitter was used as an approach similar to snowball sampling. Chapter 3 provided a detailed description of the Twitter recruitment strategy, the outcomes of this strategy and a demographic comparison of ACCs recruited through Twitter versus other convenience sampling strategies. Chapter 4 reported on ACCs’ experiences with online and in person peer support using a qualitative approach. Chapter 5 outlined the influence of peer similarity on perceived support using a mixed method approach that entailed measuring the strength and direction of peer similarity’s influence on perceived support (while controlling for other variables selected based on the Interactional Cognitive Model of Social Support (48)) and interviewing ACCs to explore their perspectives on peer similarity and how it influences the peer support relationship.
6.3 Summary of Findings

Chapter 3 reported the use of Twitter to recruit carers. In total, 1715 study-related tweets were posted resulting in 27 of 71 carers being recruited through Twitter. Tweet categories included ‘general recruitment’, ‘mention’ and ‘engagement’ tweets. General recruitment tweets were most-shared by users (67.2% were retweeted). The top 10 most retweeted tweets indicated that tweet reach can range from 5,273 to 62,144 users. No demographic differences were identified between carers recruited through Twitter versus other convenience sampling strategies. Effect size estimates of the differences between recruitment strategies were small.

In Chapter 4, 15 ACCs participated in in-depth qualitative interviews. ACCs predominantly mobilized their existing network for peer support. Thematic analysis of the narrative data suggested that ACCs are pragmatic in their approach to peer support in as far as they use a blend of communication modalities to meet their various needs. As a result, the nature of support received from peers was consistent across modalities.

In Chapter 5, 71 ACCs completed the web-based survey and 15 were interviewed. A hierarchical regression analysis indicated that peer similarity was positively and significantly associated with perceived support and explained variation in perceived support above and beyond other covariates. The qualitative data confirmed these findings, indicating that similarity to a peer was important to ACCs overall but also added that ‘shared caregiving experience’ was the single most important aspect of similarity. Shared caregiving experience optimized ACCs’ relationships with peers as well as the support received.
6.4 Integrated Discussion

6.4.1 Peer support as it pertains to the adult children carer (ACC) population

As mentioned previously, ACCs are unique in that they have multiple and competing age-normative responsibilities that can make caregiving especially stressful. In fact, ACCs are often referred to as the “sandwich generation”—characterized by their responsibilities to their own children, aging parents and other life aspects (e.g. spouse, employment) (173). Given that an entire ‘generation’ of carers belongs to this group, it is not surprising that ACCs were able to identify and mobilize members of their existing network of family and friends for peer support. That is, current demographic trends may increase the likelihood that ACCs already know others that can serve as peer supports when caregiving presents itself. This highlights that future peer support interventions must tailor their structure and delivery to the caregiving population being served.

Another by-product of being part of the ‘sandwich generation’ is that ACCs face common challenges such as balancing work, family and care responsibilities (174;175) and restricting participation in valued activities (24). For this reason, adult children carers—more so than other caregiving populations—may be a relatively homogenous group. In turn, basic similarities in demographics and lifestyle might explain why these domains did not stand out as important in comparison to similarity in caregiving experience. The significance of shared caregiving experience to ACCs may also be explained by the context of support. As mentioned, ACCs predominantly mobilized their existing networks for support. This reinforces research that suggests carers benefit from ‘shared caregiving experience’ only when it comes from naturally-occurring networks rather than artificially formed ones (176). This is echoed in the discrepancy
between interventional studies that have found no objective benefit to matching caregiving peers based on similarities and research that suggests peer similarity promotes well-being in naturally-occurring networks (38). This once again underscores the need to reconsider our strategies for supporting this caregiving population.

6.4.2 The relational aspect of peer support

Little research to date has focused on exploring the nature and extent of the peer support relationship within the caregiving context. Although the predominant focus of this research was on understanding ACCs’ support experiences (e.g. online vs. in person experience; how peer similarity influences perceptions of support), the qualitative approach taken allowed new data to emerge highlighting that the quality of the relationship ACCs had with their peers was of high importance. ACCs valued intimacy, connectedness and honesty in their peer relationships and chose the communication modality they felt best enabled these relationship qualities. The notion of ‘connectedness’ was also echoed in Chapter 5 where ACCs described ‘shared caregiving experience’ as bringing them together with their peers. Shared caregiving experience was also described as adding breadth and depth to the peer relationship and enhancing reciprocity. These aspects pertain to ‘relationship quality’—a topic that has been broadly investigated in the caregiving literature.

Caregiving research has paid close attention to the notion of relationship quality and its role in various aspects of the caregiving situation. Several studies have suggested that the pre-caregiving relationship between the carer and care-recipient has important implications for post-caregiving relationship quality (177;178) and carer health outcomes (179). In a filial context, parent-child relationship quality may impact who the parent selects as their primary carer (180). Further, the nature of the relationship between siblings before caregiving can influence the
quality of their relationship during caregiving as well as their ability to agree on parent care (181). Taken together, these findings as well as those from the current study suggest that ‘relationship quality’ in a carer peer support context should not be overlooked.

The temporal aspect of relationship quality (i.e. changes in and influence of the pre-caregiving relationship) may be of particular importance to the ACC population since those in this study predominantly mobilized members of their network for support. This implies that a relationship existed with these individuals prior to the uptake of the caregiving role. This can have important implications for how the post-caregiving relationship changes and evolves over time.

6.4.3 The nature of communication

Findings from chapter 4 indicated that carers use a blend of communication modalities to interact with peers. In turn, dichotomizing online and in-person communication may not be a fruitful way to understand peer support patterns amongst adult children carers. Given that they communicate across these modalities and utilize both for different purposes, our efforts should focus less on distinguishing between these modes of interaction and more on integrating them to enhance support delivery.

Although the current study focused on online and in-person communication, carers also mentioned texting and phone calls as additional modalities for peer support engagement. Carers felt that phone communication was similar to face-to-face interaction due to voice cues, and that texting was similar to sending an email but shorter and often more convenient. This suggests that a sort of ‘continuum of communication’ may exist. Texting and phone calls lie somewhere in between what is strictly ‘in-person’ or ‘online’ communication. This is especially true given the popularity of smart phones and mobile apps, which both integrate elements of Internet, written
messaging (i.e. texts), visual contact (e.g. FaceTime on iPhone or Skype), as well as calling. Overall, the communication-related findings from this study begin to elucidate the need to reconceptualise peer support interaction and support delivery as it pertains to 21st century trends and digital innovation.

6.5 Implications

Caregiving and carer support are topics that span the theory, research, practice and policy realms. The present research was guided by the Interactional Cognitive Model of Social Support (ICMSS). By contextualizing the study findings within this model, a number of theoretical implications are made below. The findings highlighted areas that would benefit from future exploration. These are outlined in terms of research implications. The study also elucidated potential ways that clinicians and community care workers can intervene with the ACC population. In turn, practice implications are discussed. Similarly, implications for caregiving policy are discussed based on the study results.

6.5.1 Theory (Interactional Cognitive Model of Social Support)

1. In the present study, interpersonal factors influenced the social support process more so than those within the situational and intrapersonal domains of the Interactional Cognitive Model of Social Support (ICMSS) (48). This was evident from both the quantitative data (e.g. peer similarity accounting for variation in support perceptions above and beyond other situational and intrapersonal factors) and the qualitative findings (e.g. carers receiving the same type and quality of support across communication modalities, peer similarity improving support and relationship quality). This highlights that in the context of peer support amongst carers, interpersonal considerations may warrant more attention in terms of research and intervention than other factors that fall within the situational or intrapersonal domains.
2. Shared caregiving experience was the most important aspect of similarity to ACCs as it enhanced their peers’ understanding of and sensitivity to their circumstances. In turn, this fostered higher quality relationships and improved support. In line with the ICMSS, this underscores that social support is not simply an objective outcome of social interactions but that it also reflects the match between an individual’s needs and the response made by support providers (i.e. interpersonal sensitivity) (49).

3. The ICMSS explains that the social support process is better understood when the recipient, provider and their relationship are all studied (182). However, the nature and extent of the relationship between caregiving peers has been largely overlooked. This is especially problematic given that shared caregiving experience (as an aspect of peer similarity) influenced the quality of the relationship between ACCs and their peers. Further, ACCs mobilized their existing network for support indicating that a pre-caregiving relationship existed. The nature of the pre-caregiving relationship has important implications since the effect of support given to individuals varies based on the provider and recipient’s relationship history (182).

4. Some research suggests that the effectiveness of support interventions depends on their context, with certain actions being perceived as helpful from some but not other network members (183). Our findings build on this and suggest that network members with whom ACCs shared similarities were perceived to be better sources of support. This aligns with the ICMSS’ assertion that supportive efforts are successful only under certain circumstances and depend on the nature of the relationship between the support provider and recipient (184). Building on past recommendations, the present study begins to elucidate not only the type of support that carers receive but who they have received it from and the nature of the interaction with that individual (183).

5. ACCs in this research reported high levels of perceived support and discussed overwhelmingly positive interactions with peers. Moreover, they felt that shared caregiving experiences strengthened their relationship with peers and enhanced the support received. In this way, the findings don’t reflect the influence of the interpersonal context on social support when conflict between peers exists. This is an important considerations given that supportive interactions in the context of poor quality...
relationships (e.g. characterized by conflict) can result in negative supportive perceptions that increase rather than decrease stress (184).

### 6.5.2 Research

1. Since ACCs mobilize existing network members for support, a pre-caregiving relationship with their peer inherently exists. Future research with this caregiving population may benefit from exploring how these peer relationships evolve from friendships to ones that incorporate the caregiving experience and supportive exchanges. Studies can also explore how these relationships improve, deteriorate or remain the same once the caregiving role is introduced. This can inform interventions that help sustain or improve relationship quality between caregiving peers.

2. There is increasing recognition in the health sciences that peer support—as a naturally-occurring phenomenon—is difficult to replicate as a structured intervention due to the variability in how it develops and evolves (185;186). Peer support interventions are even more challenging to evaluate given that evidence-based medicine (with the RCT as the gold standard) has received criticism for lacking real-word application in this field (186). RCT designs that randomize carers to pre-determined conditions may not align with the naturally pragmatic, flexible and self-driven manner by which ACCs engage in peer support. In turn, future studies may consider alternative designs when implementing and evaluating peer support interventions. Some research has already begun to suggest a shift towards “pragmatic trials” where the goal is to test interventions in everyday clinical settings in order to enhance their applicability and generalizability (187;188). A pragmatic trial aims to answer the question of whether an intervention actually works in ‘real life’ (187). One way that an RCT can be modified to be more pragmatic is by taking participant preference into account (e.g. allowing participants to choose an intervention arm and only randomizing them if they have no preference) (188). Preference RCTs can provide greater evidence of the external validity of trial findings and may motivate more individuals to participate in clinical trials (189;190). This may be especially beneficial for peer support interventions given that ACCs’ preferences and needs influenced who they interacted with and how.
6.5.3 Practice

1. In this research, the nature of support received by ACCs was in line with the support that would typically be delivered in an intervention (i.e. emotional, informational, appraisal support). This suggests that in order to be comparable to carers’ natural peer support engagement, interventions must be flexible in the way they deliver support (e.g. use multiple modalities) in order to align with carers’ communication preferences and meet their diverse support needs. The need for interventions to be responsive and adaptable underscores the growing recognition that a ‘one-size-fits-all’ approach does not suit carer support (191-193).

2. The present findings suggest that there may be a wealth of peer support available to ACCs within their existing network of friends and family. Future interventions can help ACCs identify peers and facilitate their mobilization of these individuals for support. In turn, this capitalizes on ACCs’ existing resources rather than introducing artificial networks for investigative purposes (194). Alternatively, clinicians and community care workers can ‘flag’ ACCs that may be ‘at-risk’ due to having limited peer support available to them. These carers may require a different approach that entails directing them towards supportive resources (e.g. online networks or in-person support groups) in order augment or develop peer networks.

6.5.4 Policy

1. A 2012 Ontario Care Watch Report estimated that every 10% shift of patients from acute care (waiting for long-term care) to home care would result in $35 million in savings (195). The report highlighted, however, that his would require substantial investment from the Ministry of Health and Long-term Care into home and community care (195). This shift to home care places greater expectations on family carers as they become primarily responsible for helping elders remain at home (196). Despite this, the contributions of family carers are often overlooked in home care policy (195). A recent citizen’s panel highlighted the importance of supporting family carers to deal with the emotional, physical and economic burden of caregiving (196). Technological innovation (e.g. web-based programming) has been recommended as a means of supporting patients and their carers in the community due to its ability to drive and enable change (196).
present findings suggest that ACCs effectively use the online realm to seek peer support in order to meet their practical needs. This underscores that people are becoming increasingly comfortable with technology in their daily lives and that technology can be used to deliver support in an affordable and accessible manner (196). As has been mentioned, it may be more beneficial to capitalize on ACCs’ existing peer networks rather than introduce artificial ones. For example, Tyze is an online personal network program that helps carers coordinate and communicate with existing caregiving peers, care-receivers as well as formal services (197). Tyze has interventional potential with the ACC population as it can aid them in managing their existing network. In turn, ACCs can benefit from the support their network has to offer. Home care policies that support technology-based innovations can help to ensure the integration of programs such as Tyze into home care and support delivery (196).

2. The Carer Policy Lens emphasizes the importance of shifting towards policies that are informed not only by the cost-reduction aspects of a program, but also by evidence that values caregiving and carer needs in their own right (198). As has been previously pointed out, traditional research methods aimed at developing and evaluating structured interventions may not be appropriate for peer support delivery—especially amongst ACCs. This may explain why peer-matching interventions have shown little to no impact on carer health outcomes (170). It can be expected that such interventions will similarly have little cost-saving value. However, the absence of peer support can have important and negative implications for carers’ social health and well-being. In turn, the costs and consequences of ignoring the limitations of existing policies and programs must also be evaluated (198).

3. The present findings suggest that adult children are able to mobilize existing networks for peer support. ACCs described receiving peer support from networks they built through everyday activities (e.g. socializing with friends, spending time with family, engaging with co-workers). In turn, policies that help ACCs sustain their participation in these valued activities can also enable them to obtain peer support. To help carers maintain employment, workplace policies have been suggested to include flexible work hours,
virtual workspace, and paid leave (197). Policies that promote social engagement have been suggested to include the provision of respite and financial aid services (197).

6.6 General Limitations

The specific limitations of each aspect of the study can be found in their corresponding chapters. However, a few overarching limitations may also impact the overall understanding of the research and its implications. Firstly, to be eligible to participate in the study, ACCs had to be in contact with another caregiving (i.e. a peer). While this ensured that ACCs had peer support experiences they could reflect on, it simultaneously restricted the ability to capture a wider range of experiences from ACCs who have limited peer supports. Possibly stemming from this, another limitation was that ACCs in this research had overwhelmingly positive experiences with peer support. This may be because most reflected on peer relationships were many similarities were shared and in turn, support was optimized. Regardless of the mechanism, this homogenous element of the sample limits our understanding of how ACCs’ peer support engagement may differ in circumstances of support dissatisfaction or lack of peer support. Several other characteristics rendered the sample of ACCs relatively homogenous. The large majority of participants were adult daughters and although this is consistent with caregiving demographic trends, it indicates that findings are not necessarily representative of adult son carers’ peer support experiences. Participants were largely well-educated and had relatively high household incomes. In turn, this limits the transferability of findings to ACCs with lower socioeconomic status. Finally, because this research was conducted in English, it does not reflect caregiving situations where English is not the primary language.
6.7 Concluding Statement

This dissertation aimed to understand adult children carers’ (ACCs) online and in person experiences with peer support and the role that peer similarity plays in influencing perceptions of support. Within the context of this research, a methodologically-oriented study was conducted that described the use of Twitter as an innovative recruitment avenue. Twenty-seven (38%) ACCs were recruited using Twitter and were found to be comparable—in terms of demographics and Internet proficiency—to those recruited through other convenience sampling strategies. Additional findings begin to elucidate that ACCs primarily mobilize their existing network of friends and family to obtain peer support. Findings also suggest that ACCs use a combination of communication modalities to meet their practical and relational support needs. As a result, the nature of support received by ACCs transcends the modality of communication. It was also highlighted that more similarity between peers is significantly associated with higher ratings of perceived support. Shared caregiving experience was the single most important aspect of peer similarity and optimized both the peer support relationship and support received. These findings suggest that future interventions should incorporate multiple communication modalities to facilitate peer-to-peer interaction, focus on augmenting existing networks of support rather than introducing new ones and ensure that the various aspects of shared caregiving experience are comprehensively accounted for.
7 References


(24) Bastawrous M, Gignac MA, Kapral MK, Cameron JI. Adult daughters providing post-stroke care to a parent: a qualitative study of the impact that role overload has on lifestyle, participation and family relationships. Clinical Rehabilitation 2015;6(29):592-600.


(34) Uchino BN. Understanding the Links Between Social Support and Physical Health: A Life-Span Perspective With Emphasis on the Separability of Perceived and Received Support. Perspectives on Psychological Science 2009 May 1;4(3):236-55.


(69) Smyth KA, Harris PB. Using telecomputing to provide information and support to caregivers of persons with dementia. Gerontologist 1993;33(1):123-7.


Harrell FE. Regression modeling strategies: with applications to linear models, logistic regression and survival analysis. 2001.


Horowitz A. Sons and Daughters as Caregivers to Older Parents: Differences in Role Performance and Consequences. Gerontologist 1985 Dec 1;25(6):612-7.


Patton MQ. Qualitative evaluation and research methods. SAGE Publications, inc; 1990.

Canadian Virtual Hospice. 'About Us'. 2012.


(100) IBM. IBM SPSS Missing Values 22. 2016. 2-12-2016.


(104) NVivo Qualitative Data Analysis Software [computer program]. Version 10 QSR International Pty Ltd.; 2010.


125


(119) Lafferty NT, Manca A. Perspectives on social media in and as research: A synthetic review. Int Rev Psychiatry 2015 Mar 5;1-12.


(125) Frandsen M, Walters J, Ferguson SG. Exploring the viability of using online social media advertising as a recruitment method for smoking cessation clinical trials. Nicotine & tobacco research 2014;16(2):247-51.

(126) Graham AL, Milner P, Saul JE, Pfaff L. Online advertising as a public health and recruitment tool: comparison of different media campaigns to increase demand for smoking cessation interventions. Journal of Medical Internet Research 2008;10(5).


(170) Pillemer KK, Suitor JJJ. "It takes one to help one": effects of similar others on the well-being of caregivers. The journals of gerontology Series B, Psychological sciences and social sciences 1996 Sep;51(5):S250-S257.


(181) Woolley M. Parenting and Relationship Predictors of Adult Siblings Collaborating in the Care of Aging Parents.: Sswr; 2015.


Cohen SA. Demographic and socioeconomic modifiers of the association between caregiving intensity and caregiver health: Evidence from a national caregiving survey. APHA; 2015.


Appendices

Appendix A: Piloting and evaluating the feasibility of planned recruitment strategy

Rationale

We conducted a pilot run of the recruitment strategy in order to determine its feasibility. Evaluating the feasibility of the present study’s recruitment strategy was particularly important as we aimed to implement a two-pronged strategy entailing both online and in-person recruitment which has not been tried with this population. As we did not want to exhaust all of our online and in-person resources, we carefully selected approaches that would be smaller-scale representations of the full strategy (See Chapter 4).

Procedure

To pilot our online recruitment strategy, a Facebook page was created and ads were posted from December 2013 to January, 2014. Study information was also distributed through Canadian Virtual Hospice’s January 2015 eNews (an email newsletter sent to members monthly). The Canadian Virtual website has over 25,000 visitors per month, with a rapidly growing population of carers to aging parents (3). The website provides educational content as well as blogs, online support groups and social media engagement.

To pilot the offline recruitment strategy, Toronto Family Services’ carer support group was used to distribute study information. Participant eligibility and study procedure were the same as the full study. The sample size required for the quantitative phase of the full study was 80 participants. As has been recommended by previous literature, our goal was to recruit 10% of this latter sample size for the feasibility evaluation (4). As such, we aimed to recruit a total of 8
participants. All 8 participants would be directed to the online survey to complete a battery of quantitative measurement instruments (described in the ‘data collection’ section of Chapter 4).

**Evaluation criteria**

As previous literature has suggested, specific feasibility and acceptability goals should be set *a priori* (5;6). As such, we evaluated the recruitment strategy to determine whether the following feasibility criteria were met (7).

1) Recruitment: 8 carers are recruited within 2 months
2) Eligibility criteria: ≥60% of carers who express interest in study are eligible
3) Completion rates: ≥90% completion rate (i.e. 90% or more of those who are eligible and consenting will complete survey)
4) Ease of use of questionnaires and interview: ≤10% missing data in each completed questionnaire (quantitative)
5) Study process: No more than 2 protocol deviations with 6 carers (i.e. accidental/non-intentional changes to or non-compliance with research protocol)
6) Time to complete survey: ≤1 hours

Based on a protocol by Kramer et al (2013), the following guidelines were used to determine whether the recruitment approach was feasible (8):

- 0-2/6 criteria met - Stop; study design not feasible.
- 3-4/6 criteria met - Continue with modifications; feasible study design with modifications.
- 5/6 criteria met - Continue without modifications, but monitor closely; feasible study design with close monitoring.
- 6/6 criteria met - Continue without modifications; feasible study design as is.

**Outcome of Evaluation**

During the 1 month pilot evaluation, 69 individuals accessed the study survey. Out of the 6 criteria we evaluated, 4 (67%) were met:
• Criteria 3: All 3 participants who were eligible and consented to participate completed the entire survey (100% completion)
• Criteria 4: No survey data was missing for completed questionnaires
• Criteria 5: No protocol deviations were noted
• Criteria 6: The survey took less than 1 hour to complete (average of 26.5 minutes)

Criteria 1 and 2 however were not met. While we aimed to recruit a minimum of 8 carers within 2 months, we were only able to recruit 2 (25%). It was our goal that at least 60% of carers who accessed the survey would be eligible to participate. Of the 69 individuals that accessed the survey, 15 (22%) did not answer the eligibility questions in their entirety. Of the remaining 54 individuals, only 12 (22%) were eligible to participate.

**Evaluation-based revisions to protocol**

Based on the guidelines by Kramer et al (2013), with 4 out of 6 criteria met, our recruitment design was considered feasible but modifications needed to be made in order to proceed.

*Modifying Criteria 1: Recruit six carers per month*

Given that we were only able to recruit 2 carers in the span of 2 months, we determined that there was a need to expand our recruitment strategy. We expanded our social media recruitment to include Twitter. This allowed us to expose the study to a larger population of carers and relevant stakeholders. Within this modality, we were able to send out ‘tweets’ with the study link and ask other users to ‘retweet’ the message. This is synonymous with snowball sampling through word-of-mouth but with more exposure and amplification due to the high usage of Twitter nationally and globally. Detailed insight into the Twitter recruitment approach and outcome can be found in Chapter 6).
Modifying Criteria 2: ≥60% of carers who express interest will be eligible for study

Since only 22% of individuals who accessed the survey within the 2 month pilot period were eligible for the study, we determined that the inclusion and exclusion criteria needed to be relaxed. Initially, we were targeting carers providing assistance to community-residing parents. However, to broaden the potential pool of participants, we eliminated this criterion. We also initially planned to exclude carers providing palliative or end-of-life care but once again eliminated this criterion in order to enhance recruitment. The reason these criteria were set initially was because some studies report that the caregiving experiences of those providing end-of-life care or care to an institutionalized loved one are different from those providing on-going community based care. We were cognizant of the fact that eliminating these criteria may add a greater deal of heterogeneity to our sample but considered this a necessary trade-off in order to reach a sample size sufficient enough to perform our analyses. Since we were also collecting qualitative data, we felt that we would be able to identify and explore any outlying experiences that appeared to be a result of the caregiving circumstances (i.e. community-based, end-of-life or institutionalized).

From participants’ answers, we noticed that many were responding ‘no’ to the inclusion criteria question: “Are you caring for a parent” but then answering ‘yes’ to the inclusion criteria question: “Do you assist your parent with at least 1 activity at least once a week (e.g. dressing, feeding, grocery shopping, driving to appointments, managing finances)?” For the purposes of our study, we were conceptualizing a ‘carer’ as someone who provided assistance to the care-recipient with an activity at least once a week. As a result, to reduce confusion and increase recruitment, we eliminated the question “Are you caring for a parent?”
Appendix B: Recruitment Brochure

Are you 18+ and providing care to a parent?  

Do you interact with other caregivers online or in person?

The goal of the study: To learn about the peer support relationship between adult children caregivers who interact online or in person.

Who can participate: Individuals who are: 1) 18 years or older; 2) Helping their mom/dad with any of their usual activities or medications and 3) Interacting with caregiving peers online or in person.

Your role: To answer an online survey that should take 30-45 minutes to complete. You will be able to start and resume the survey at any time and therefore do not need to finish it all at once. At the end of the survey, you will be invited to participate in an optional 45-60 minute telephone interview. The interview aims to gain more in-depth information about your experiences as a caregiver and the relationship between you and your peers. The interview is optional and you may choose to only complete the survey.

To learn more about the study and to access the survey please visit:  

http://fluidsurveys.com/s/caregivingstudy/

For more information: Contact Marina at 416-978-5694 or marina.bastawrous@utoronto.ca
Appendix C: Consent Form

Informed Consent Form for Participation in a Research Study: Family Carer Consent Form

STUDY TITLE: Online and in-person interaction between adult children carers: A mixed method inquiry into the peer support relationship

INVESTIGATOR:
Marina Bastawrous, PhD(c), MSc: 416-978-5694 or marina.bastawrous@utoronto.ca
Supervisor: Jill Cameron, PhD: 416-978-2041 or jill.cameron@utoronto.ca

You are being asked to take part in a research study. Before agreeing to participate in this study, it is important that you read and understand the following explanation of the proposed study procedures. The following information describes the purpose, procedures, benefits, discomforts, risks and precautions associated with this study. It also describes your right to refuse to participate or withdraw from the study at any time. In order to decide whether you wish to participate in this research study, you should understand enough about its risks and benefits to be able to make an informed decision. This is known as the informed consent process. Please ask the study investigator or study staff to explain any words you don’t understand before signing this consent form. Make sure all your questions have been answered to your satisfaction before signing this document.

Purpose
The purpose of this study is to explore how adult children carers interact with their peers online and in person. Specifically, this study aims to understand how perceptions of being supported by a specific peer are influenced by: a) similarity between peers; b) the strength of the ties they form and c) how they interact (e.g. in person or online).

Objectives
To explore the peer support relationship between adult children carers and understand how peer-similarity, tie strength and networking modality (i.e. online vs. in-person) contribute to perceptions of being supported by a specific peer.

Procedures
If you decide to participate in this study, you will be asked to fill out a survey that should take about 30-45 minutes to complete. This survey will ask you about: your background, your parent’s health, the amount and type of care you provide to your parent, your caregiving peers, your similarity to a specific peer, the strength of the relationship between you and that peer and the support you receive from that peer. This interview will be completed online and you will require a computer to access it. Upon completing this survey, you will be asked if you would like to participate in an optional telephone interview that should take approximately 45-60 minutes to complete. Should you choose to participate, you will be asked for your contact information (e.g. phone number, email address) and the researcher will later contact you to arrange for an interview time. This interview will ask about your experiences with interacting with caregiving peers either online or in person and will ask you to elaborate on some of the topics that were introduced in the online survey (e.g. how similar you feel to a peer and why, how being similar to a peer impacts the strength of your relationship, how similarity with a peer and tie strength influence support received form this peer).

Risks
Carers participating in our study will be asked to reflect on their experiences while providing care to an elderly parent and receiving support from caregiving peers. There is a possibility that reflecting on these things may be upsetting for carers. To off-set any discomfort caused by the questions in the survey and interview, carers will be free to skip any questions they are not comfortable answering in the survey and can inform the researchers during the interview if a question is asked that they do not wish to answer or elaborate on. During the interviews, researchers are prepared to help participants who may have a strong emotional response to the interviews by giving them information about people who are trained to talk to them about how they are feeling. There are no other significant risks to participating in this study.

Benefits
You may benefit from discussing your experiences, emotions, and concerns to an attentive listener. Although you may not directly benefit from the results of this study, you may benefit from knowing that your participation can contribute to enhancing peer support programs for carers who take on the parent care role in the future.

Confidentiality
Any information that is collected from you online for the purposes of the study will be stored securely at the University of Toronto. Any hard-copy information that is collected for the study will be kept in a locked and secure area by the study researchers for 7 years. Only the study team and the people at the University of Toronto Research Ethics Boards will be allowed to look at these records. After the 7-year period, all electronic and physical information will be destroyed by Dr. Jill Cameron.
Any information about you that is sent out of the University of Toronto (Example: to be used in presentations, conferences, or written summaries of the research) will not show your name or address, or any information that directly identifies you. All information collected during this study will be kept confidential and will not be shared with anyone outside the study unless required by law.

If you decide to leave the study, the information you provided will be retained but no new information will be collected. If you wish for the information you provided to be deleted, you may contact the researchers and they will remove your information from the data set.

Participation
Your participation in this study is voluntary. You can choose not to participate, refuse to answer a question, or leave the study at any time without penalty or loss of benefits to you or to the person you are caring for.

Compensation:
In no way does signing this consent form waive your legal rights nor does it relieve the investigators, sponsors or involved institutions from their legal and professional responsibilities. You will not be compensated for time associated with study participation.

Questions
If you have any general questions about the study, please call graduate student Marina Bastawrous at 416-978-5694 or her supervisor Dr. Jill Cameron at 416-978-2041

If you have any questions about your rights as a research participant, please contact the University of Toronto Office for Research Ethics at: ethics.review@utoronto.ca or 416-946-3273. The Office for Research Ethics is not involved with the research project in any way and calling them will not affect your participation in the study.

Consent (please click one of the following)

☐ I do not wish to participate in the study at this time and decline to provide my consent.

☐ I consent to take part in the study. I may withdraw at any time without it affecting me or the medical care of my loved one. I have printed a copy of this consent form for my records. I voluntarily consent to participate in this study
Appendix D: Visual Summary of Interactional Cognitive Model of Social Support

PERCEIVED SUPPORT

Situational
- Social & Psych environment

Interpersonal
- Expectations maintained about specific relationships & extent to which those relationships are seen as supportive

Intrapersonal
- Individual’s predisposition to engage in & interpret social behaviors

• Geographic distance
• Carer assistance
• Parental dependency

Peer similarity

• Frequency of contact
• Duration of relationship

• Self-disclosure
• Mastery
• Extraversion
• Problem/emotion-based coping
<table>
<thead>
<tr>
<th>Construct</th>
<th>Survey</th>
<th>Approx. time to complete</th>
<th>Author(s)</th>
<th>Test-retest reliability</th>
<th>Internal consistency</th>
<th>Convergent validity</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>α = 0.94</td>
<td>r = 0.66-0.82</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>α = 0.83-0.91</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>α = 0.83</td>
<td>r = 0.71 [with depth scale]</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>α = 0.79</td>
<td>r = -0.31 [with conflict scale]</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>α = 0.83</td>
<td>r = 0.21 [with investigator-determined similarity]</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(90)</td>
<td>(75)</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>r = 0.58-0.72</td>
<td>α = 0.57-0.90</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>α = 0.70</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td>α = 0.81</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>(28)</td>
<td>(91)</td>
<td></td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
<td>r=0.81</td>
<td>α = 0.75</td>
<td></td>
</tr>
</tbody>
</table>
Appendix F: Demographic Questionnaire

Socio-demographic and health-related information

1. How did you hear about this study?
   a) Facebook
   b) Twitter
   c) Local support group
   d) Canadian Virtual Hospice email
   e) St. Elizabeth healthcare
   f) Canadian Carer Coalition
   g) Carer Connect
   h) Other (Please specify:______)

2. What is your age, in years? _________________

3. What is your gender (select one):  a. Male     b. Female

4. In which Country were you born? ___________________

5. What is your ethnicity?
   a) White
   b) Chinese
   c) South Asian
   d) Black
   e) Filipino
   f) Latin American
   g) Southeast Asian
   h) Arab
   i) West Asian
   j) Korean
   k) Japanese
   l) Other: ______________________

6. What was the first language you learned as a child? _________________

7. Where do you currently live?
   Province:
   Alberta
   British Columbia
   Manitoba
   New Brunswick
   Newfoundland and Labrador
   Northwest Territories
   Nova Scotia
   Nunavut
   Ontario
Prince Edward Island
Quebec
Saskatchewan
Yukon

City: ______________________

8. Which parent are you primarily caring for?
   a) Mother
   b) Father

9. What are your parent’s main health concerns? [Select all that apply]
   a) Stroke
   b) Cancer
   c) Dementia
   d) Alzheimer’s Disease
   e) Diabetes
   f) Multiple Sclerosis
   g) Heart Attack
   h) Pulmonary Disease
   i) Liver Disease
   j) Parkinson’s Disease
   k) Aging-related
   l) Other: ______________________

Is your parent treated for any other health conditions? (Please select all that apply)

1. Hypertension
2. Heart attack (MI)
3. Angina
4. Stroke
5. Hemiplegia
6. Bronchitis
7. Emphysema
8. Asthma
9. Arthritis
10. Ulcer disease
11. Diabetes
12. Glaucoma
13. Cataracts
14. Impaired hearing
15. Parkinson’s disease
16. Thyroid problem
17. Cancer (specify type, location)
18. Liver disease
19. Other, specify, _______________

10. What is your marital status?
   1) Single
   2) Married/common law
   3) Separated
   4) Divorced
   5) Widowed

11. Do you have children?  
   1) Yes  
   2) No

   If yes, how many? ______________________
What are their ages (in months)? Years _________  Months__________

12. Do you currently live with your parent?
   (1) Yes, full time  (2) Yes, part time  (0) No

13. How long have you been providing home care (this time only)?__________months

14. Prior to this time, have you provided care before?(for this parent or someone else)
   (1) Yes       (2) No
   If yes, for whom: ___________________ and for how long: ________________

15. What is your current primary daily activity? (Please choose one)
   a. carer
   b. homemaker
   c. working for pay : type of work?_______________ hours/week?__________
   d. unemployed
   e. receiving disability
   f. retired
   g. volunteer
   h. student

16. If you are working with paid remuneration or unpaid (regular volunteering), has your
    status changed since your care-giving role?  (1) Yes       (2) No
    If yes, how has your paid employment / volunteer activities changed? Please check all
    that apply:
    a. quit working/volunteering : specify previous job ________________
    b. changed job : specify new job_______________________
    c. took unpaid leave of absence for _________weeks
    d. took paid leave of absence for _________weeks
    e. decreased hours of work/volunteering by __________hours/week
    f. increased hours of work/volunteering by ____________hours/week
    g. started working/volunteering outside the home : specify new job________
    h. opened home business : specify type_______________________________
    i. other (specify) : ________________________________________________

17. What is the highest level of education you have completed? (Please choose one)
   a. Less than primary (grade 8)
   b. Completed primary
   c. Less than secondary
   d. Completed secondary
   e. Some College courses
   f. Completed College
   g. Some university
   h. Completed university (bachelor degree)
   i. Post undergraduate program
18. Which of the following categories best describe your family income?

a) Less than $10,000
b) $10,000 to $19,999
c) $20,000 to $29,999
d) $30,000 to $39,999
e) $40,000 to $49,999
f) $50,000 to $59,999
g) $60,000 to $69,999
h) $70,000 to $79,999
i) $80,000 to $89,999
j) $90,000 to $99,999
k) $100,000 to $149,999
l) $150,000 or more
m) Pass

19. HEALTH ISSUES - please check all that apply to YOU

Please indicate whether you are presently treated for any of the identified conditions. Please select all that apply.

(1) Hypertension (11) Diabetes
(2) Heart attack (MI) (12) Glaucoma
(11) Angina (13) Cataracts
(12) Stroke (14) Impaired hearing
(13) Hemiplegia (15) Parkinson’s disease
(14) Bronchitis (16) Thyroid problem
(15) Emphysema (17) Cancer (specify type, location) _____________
(16) Asthma (18) Liver disease
(17) Arthritis (19) Other, specify____________
(18) Ulcer disease
## Appendix G: Carer Assistance Scale (CAS)

We would like to know **how much assistance** you provide to the care recipient for each of the following activities, a rating of zero (0) indicates “no” assistance is provided, while a rating of six (6) indicates “a lot” is provided.

Please answer all questions to indicate your experience **since you began providing care for your parent**.

1. How much assistance do you provide in **transportation** (e.g., to and from hospital)?
   - 0 None
   - 1
   - 2
   - 3
   - 4
   - 5
   - 6 A Lot

2. How much assistance do you provide in **giving medications/assisting with treatment**?
   - 0 None
   - 1
   - 2
   - 3
   - 4
   - 5
   - 6 A Lot

3. How much assistance do you provide in **banking and financial management**?
   - 0 None
   - 1
   - 2
   - 3
   - 4
   - 5
   - 6 A Lot

4. How much assistance do you provide in **feeding**?
   - 0 None
   - 1
   - 2
   - 3
   - 4
   - 5
   - 6 A Lot

5. How much assistance do you provide in **dressing**?
   - 0 None
   - 1
   - 2
   - 3
   - 4
   - 5
   - 6 A Lot

6. How much assistance do you provide in **grooming** (e.g., combing hair, brushing teeth)?
   - 0 None
   - 1
   - 2
   - 3
   - 4
   - 5
   - 6 A Lot

7. How much assistance do you provide in **toileting** (e.g., going to bathroom)?
   - 0 None
   - 1
   - 2
   - 3
   - 4
   - 5
   - 6 A Lot

8. How much assistance do you provide in **bathing**?
   - 0 None
   - 1
   - 2
   - 3
   - 4
   - 5
   - 6 A Lot
9. How much assistance do you provide in **ambulation** (e.g., walking, moving around the home)?

   0  None | 1 | 2 | 3 | 4 | 5 | 6 | A Lot

10. How much assistance do you provide in **transfers** (e.g., bed to chair, chair to toilet)?

   0  None | 1 | 2 | 3 | 4 | 5 | 6 | A Lot

11. How much assistance do you provide in **managing the emotional changes** (e.g., crying spells, mood changes)?

   0  None | 1 | 2 | 3 | 4 | 5 | 6 | A Lot

12. How much assistance do you provide in **communication** (helping with the telephone, writing, reading, explaining things)?

   0  None | 1 | 2 | 3 | 4 | 5 | 6 | A Lot

13. How much assistance do you provide in **coordinating, arranging, and managing services and resources** (scheduling appointments, arranging transportation, locating equipment and services, and finding outside help)?

   0  None | 1 | 2 | 3 | 4 | 5 | 6 | A Lot

14. How much assistance do you provide in **communicating with health professionals**?

   0  None | 1 | 2 | 3 | 4 | 5 | 6 | A Lot

15. How much assistance do you provide in **monitoring the health of the care recipient**? (e.g., weight, blood pressure)

   0  None | 1 | 2 | 3 | 4 | 5 | 6 | A Lot

16. How much assistance do you provide in **household responsibilities** (e.g. meal preparation, cleaning, yard care)?

   0  None | 1 | 2 | 3 | 4 | 5 | 6 | A Lot

17. How much assistance do you provide in **managing behaviour problems of care recipient** (e.g., irritability, irrational thoughts)?
## Appendix H: Barthel Index

These questions relate to your parent’s ability to help them self. Please answer all questions to the best of your ability by ticking one box in each section. Example:

<table>
<thead>
<tr>
<th>Bathing</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>In the bath or shower, does your parent:</td>
<td></td>
</tr>
<tr>
<td><strong>Remember – tick one box only</strong></td>
<td></td>
</tr>
<tr>
<td>manage on their own?</td>
<td></td>
</tr>
<tr>
<td>need help getting in and out?</td>
<td></td>
</tr>
<tr>
<td>need other help?</td>
<td></td>
</tr>
<tr>
<td>never have a bath or shower?</td>
<td></td>
</tr>
<tr>
<td>need to be washed in bed?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Stairs</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Does your parent you climb stairs at home:</td>
<td></td>
</tr>
<tr>
<td><strong>Remember – tick one box only</strong></td>
<td></td>
</tr>
<tr>
<td>without any help?</td>
<td></td>
</tr>
<tr>
<td>with someone carrying their walker?</td>
<td></td>
</tr>
<tr>
<td>with someone encouraging them?</td>
<td></td>
</tr>
<tr>
<td>with physical help?</td>
<td></td>
</tr>
<tr>
<td>not at all?</td>
<td></td>
</tr>
<tr>
<td>don't have stairs?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Dressing</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Does your parent get dressed:</td>
<td></td>
</tr>
<tr>
<td><strong>Remember – tick one box only</strong></td>
<td></td>
</tr>
<tr>
<td>without any help?</td>
<td></td>
</tr>
<tr>
<td>just with help with buttons?</td>
<td></td>
</tr>
<tr>
<td>someone helping them most of the time?</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Mobility</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Does your parent walk indoors:</td>
<td></td>
</tr>
<tr>
<td><strong>Remember – tick one box only</strong></td>
<td></td>
</tr>
<tr>
<td>without any help apart from a walker?</td>
<td></td>
</tr>
<tr>
<td>with one person watching over them?</td>
<td></td>
</tr>
<tr>
<td>with one person helping them?</td>
<td></td>
</tr>
<tr>
<td>with more than one person helping?</td>
<td></td>
</tr>
<tr>
<td>not at all?</td>
<td></td>
</tr>
<tr>
<td>or do they use a wheelchair independently (e.g., round corners)?</td>
<td></td>
</tr>
</tbody>
</table>
### Transfer
Does your parent move from bed to chair:

- on their own?
- with a little help from one person?
- with a lot of help from one or more people?
- not at all?

*Remember – tick one box only*

### Feeding
Does your parent eat food:

- without any help?
- with help cutting food/spreading butter?
- with more help?

*Remember – tick one box only*

### Toilet use
Does your parent use the toilet or commode:

- without any help?
- with some help but can do something?
- with quite a lot of help?

*Remember – tick one box only*

### Grooming
Does your parent brush their hair and teeth, wash their face and shave:

- without help?
- with help?

*Remember – tick one box only*

### Bladder
Is your parent incontinent of urine?

- never
- less than once a week
- less than once a day
- more often
- Or do they have a catheter managed for them?

*Remember – tick one box only*

### Bowels
Does your parent soil themselves?

- never
- occasional accident
- all the time
- or do they need someone to give them an enema?

*Remember – tick one box only*
Appendix I: Peer support context questionnaire

1) How would you rate your ability to use the Internet?
   a. Limited
   b. Basic
   c. Moderate
   d. Advanced
   e. Expert

2) How often do you use the Internet?
   a. Every day
   b. A few times a week
   c. Once a week
   d. A few times a month
   e. Once a month
   f. Less than once a month
   g. Never

We are now interested in learning about your interaction with other carers. For the rest of the questionnaire, the other carers that you interact with will be referred to as your “peers”.

3) How many caregiving peers do you interact with?
   a. Online  __________
   b. In-person  __________

4) How many caregiving peers do you interact with both online AND in-person?  __________

5) How often do you interact with caregiving peers ONLINE? (E.g. how often do you chat with carers online, respond to a carer’s blog post, Tweet a carer or post a Facebook message to a carer’s wall?)
   a. Every day
   b. A few times a week
   c. Once a week
   d. A few times a month
   e. Once a month
   f. Less than once a month
   g. Never
6) How often do you interact with caregiving peers **IN-PERSON**? (e.g. how often do you meet or talk face-to-face with a caregiving peer)
   a. Every day
   b. A few times a week
   c. Once a week
   d. A few times a month
   e. Once a month
   f. Less than once a month
   g. Never

7) Which of the following do you use to interact with caregiving peers **ONLINE**? (Please select all that apply)
   a. Blogs
   b. Facebook
   c. Twitter
   d. Email
   e. Chat rooms
   f. Skype
   g. Other: ________________
   h. Not applicable to me

8) Which of the following do you use most often when interacting with caregiving peers **IN-PERSON**? (Please select all that apply)
   a. Support groups
   b. One-on-one meetings
   c. Other: ________________
   d. Not applicable to me

9) Which one of the following best characterizes your role in **ONLINE** peer interaction? (Select one)
   a. Participator (e.g. “I like to read what carers post online, provide feedback and post about my own experiences)
   b. Observer (e.g. “I like to read what carers post online but prefer not to post about my own experiences or provide feedback too often)
   c. Not applicable to me

10) Which one of the following best characterizes your role in **IN-PERSON** peer interaction? (Select one)
   a. Participator (e.g. “I like to listen what carers have to say, provide feedback and discuss my own experiences)
   b. Observer (e.g. “I like to listen to what carers have to say but prefer not to discuss my own experiences or provide feedback too often)
c. Not applicable to me

11) Which interface do you use for the majority of your interaction with caregiving peers?
(Select one)
☐ On line
☐ In person

12) Please list the initials of 5 CAREGIVING PEERS that you interact with in the interface
you selected in the previous question (i.e. online or in-person):
1. ______________________
2. ______________________
3. ______________________
4. ______________________
5. ______________________

Please answer the following questions based on Peer # ___ with the initials _____
[RANDOMLY SELECTED]

For the caregiving peer that was randomly selected on the previous page, please answer the
following questions:

1) What is your peer’s gender?
   Male
   Female
   I don’t know

2) Which of the following age brackets best describes your peer?
   18-29 years old
   30-39 years old
   40-49 years old
   50-59 years old
   60-69 years old
   70-79 years old
   80-89 years old
   I don’t know

3) Who is your peer providing care to?
   Spouse
   Parent
   Other family member
   Friend
Other: ________
I don’t know

4) Approximately when did you start interacting with this peer?

_________       _______________  ___________
Day       Month       Year

5) How often do you interact with this peer?
   • Every day
   • A few times a week
   • Once a week
   • A few times a month
   • Once a month
   • Less than once a month

6) We are interested in learning how far away you live from your peer.

Do you know, approximately, how far away you live from your peer?

□ Yes    □ No

If yes, do you live in the:

   a) Same country: □ Yes    □ No
   b) Same province: □ Yes    □ No
   c) Same city: □ Yes    □ No
   d) Same neighbourhood: □ Yes    □ No
   e) Other:_________________________
Appendix J: Brief COPE

There are many ways to try to deal with problems. Obviously, different people deal with things in different ways, but I'm interested in how you've tried to deal with your problems. Each item says something about a particular way of coping. I want to know to what extent you've been doing what the item says (i.e. How much or how frequently).

Don't answer on the basis of whether it seems to be working or not—just whether or not you're doing it. Use these response choices. Try to rate each item separately in your mind from the others. Make your answers as true FOR YOU as you can.

1 = I haven't been doing this at all 2 = I've been doing this a little bit 3 = I've been doing this a medium amount 4 = I've been doing this a lot

1. I've been turning to work or other activities to take my mind off things.
   1  2  3  4

2. I've been concentrating my efforts on doing something about the situation I'm in.
   1  2  3  4

3. I've been saying to myself "this isn't real."
   1  2  3  4

4. I've been using alcohol or other drugs to make myself feel better.
   1  2  3  4

5. I've been getting emotional support from others.
   1  2  3  4

6. I've been giving up trying to deal with it.
   1  2  3  4

7. I've been taking action to try to make the situation better.
   1  2  3  4

8. I've been refusing to believe that it has happened.
   1  2  3  4

9. I've been saying things to let my unpleasant feelings escape.
   1  2  3  4

10. I’ve been getting help and advice from other people.
11. I've been using alcohol or other drugs to help me get through it.

12. I've been trying to see it in a different light, to make it seem more positive.

13. I’ve been criticizing myself.

14. I’ve been trying to come up with a strategy about what to do.

15. I've been getting comfort and understanding from someone.

16. I've been giving up the attempt to cope.

17. I've been looking for something good in what is happening.

18. I've been making jokes about it.

19. I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.

20. I've been accepting the reality of the fact that it has happened.

21. I've been expressing my negative feelings.

22. I've been trying to find comfort in my religion or spiritual beliefs.

23. I’ve been trying to get advice or help from other people about what to do.

24. I've been learning to live with it.
25. I've been thinking hard about what steps to take.
26. I’ve been blaming myself for things that happened.
27. I've been praying or meditating.
28. I've been making fun of the situation.
Appendix K: Pearlin Mastery Scale

How strongly do you agree or disagree with the following statements:

1. There is really no way that I can solve some of the problems I have.
   1  2  3  4
   Strongly Disagree  Strongly Agree

2. Sometimes I feel that I am being pushed around in life.
   1  2  3  4
   Strongly Disagree  Strongly Agree

3. I have little control over the things that happen to me.
   1  2  3  4
   Strongly Disagree  Strongly Agree

4. I can do just about anything I really set my mind to do.
   1  2  3  4
   Strongly Disagree  Strongly Agree

5. I often feel helpless in dealing with the problems of life.
   1  2  3  4
   Strongly Disagree  Strongly Agree

6. What happens in the future mostly depends on me.
   1  2  3  4
   Strongly Disagree  Strongly Agree

7. There is little I can do to change many of the important things in my life.
   1  2  3  4
   Strongly Disagree  Strongly Agree
Appendix L: Extraversion Questionnaire

Please rate the extent to which you agree or disagree with the following statements (1= strongly disagree and 7= strongly agree)

1. I like to have a lot of people around me

   1    2    3    4    5    6    7

   Strongly disagree       Strongly agree

2. I really enjoy talking to people

   1    2    3    4    5    6    7

   Strongly disagree       Strongly agree

3. I like to be where the action is

   1    2    3    4    5    6    7

   Strongly disagree       Strongly agree

4. I usually prefer to do things alone

   1    2    3    4    5    6    7

   Strongly disagree       Strongly agree
Appendix M: Self-Disclosure Questionnaire

In the context of a face-to-face conversation with someone, to what extent would you agree with the following statements about yourself (1= strongly disagree, 7= strongly agree)

1. I usually talk about myself for fairly long periods of time

   1   2   3   4   5   6   7
   Strongly disagree   Strongly agree

2. Once I get started, I intimately and fully reveal myself

   1   2   3   4   5   6   7
   Strongly disagree   Strongly agree

3. I often disclose intimate, personal things about myself without hesitation

   1   2   3   4   5   6   7
   Strongly disagree   Strongly agree
### Appendix N: Peer-Similarity Questionnaire

Based on the peer that was randomly selected, please rate how similar you believe he or she is to you.

For some questions you may not have complete information about what your peer is like but we would like you to **MAKE YOUR BEST GUESS**.

For each of the following questions, please select a number to indicate how similar you think your peer is to you in the stated aspect (1= similar to me; 9= dissimilar to me).

This peer is similar to me …

1. **In values**

<p>| | | | | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Similar</td>
<td>Dissimilar</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

2. **In personality**

<p>| | | | | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Similar</td>
<td>Dissimilar</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

3. **In hobbies and interests**

<p>| | | | | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Similar</td>
<td>Dissimilar</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

4. **Demographically (e.g. marital status, gender, age)**

<p>| | | | | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Similar</td>
<td>Dissimilar</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

5. **In their feelings of self-worth and self-value**

<p>| | | | | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Similar</td>
<td>Dissimilar</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

6. **In their mood and emotions**

<p>| | | | | | | | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td></td>
</tr>
<tr>
<td>Similar</td>
<td>Dissimilar</td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
7. In identifying positive aspects of caregiving (e.g. satisfaction with caregiving, benefits of caregiving)

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
</tr>
</thead>
</table>

8. In finding caregiving to be stressful

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
</tr>
</thead>
<tbody>
<tr>
<td>Similar</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>Dissimilar</td>
</tr>
</tbody>
</table>

9. In terms of the caregiving situation (e.g. who they’re caring for, amount and type of care provided, how long they’ve been providing care)

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
</tr>
</thead>
<tbody>
<tr>
<td>Similar</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>Dissimilar</td>
</tr>
</tbody>
</table>

10. In worries and concerns

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
</tr>
</thead>
<tbody>
<tr>
<td>Similar</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>Dissimilar</td>
</tr>
</tbody>
</table>

11. Overall

<table>
<thead>
<tr>
<th>1</th>
<th>2</th>
<th>3</th>
<th>4</th>
<th>5</th>
<th>6</th>
<th>7</th>
<th>8</th>
<th>9</th>
</tr>
</thead>
<tbody>
<tr>
<td>Similar</td>
<td>3</td>
<td>4</td>
<td>5</td>
<td>6</td>
<td>7</td>
<td>8</td>
<td>9</td>
<td>Dissimilar</td>
</tr>
</tbody>
</table>
Appendix O: Perceived Support Questionnaire

For the peer that was randomly selected, please answer the following questions on a scale of: 1 to 4 (1= Not at all, 2= A little, 3= Quite a bit, 4= Very much)

1. To what extent could you turn to this peer for advice about problems?

   1  2  3  4
   Not at all  Very much

2. To what extent could you count on this peer for help with a problem?

   1  2  3  4
   Not at all  Very much

3. To what extent can you count on this peer to give you honest feedback, even if you might not want to hear it?

   1  2  3  4
   Not at all  Very much

4. To what extent can you count on this person to help you if a family member very close to you died?

   1  2  3  4
   Not at all  Very much

5. If you wanted to go out and do something this evening (and geography wasn’t an issue), how confident are you that this peer would be willing to do something with you?

   1  2  3  4
   Not at all  Very much

6. To what extent can you count on this peer to listen to you when you are very angry at someone else?

   1  2  3  4
   Not at all  Very much
7. To what extent can you count on this caregiving peer to distract you from worries when you feel under stress?

<p>| | | | |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>2</td>
<td>3</td>
<td>4</td>
</tr>
<tr>
<td>Not at all</td>
<td></td>
<td></td>
<td>Very much</td>
</tr>
</tbody>
</table>
### Appendix P: Scale Reliability Analyses

<table>
<thead>
<tr>
<th>Scale</th>
<th>Number of Questions</th>
<th>Chronbach’s α</th>
<th>Level of internal consistency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Carer Assistance Scale (CAS)</td>
<td>11</td>
<td>0.89</td>
<td>High</td>
</tr>
<tr>
<td>Barthel Index</td>
<td>10</td>
<td>0.89</td>
<td>High</td>
</tr>
<tr>
<td>Brief COPE: Emotion Subscale</td>
<td>8</td>
<td>0.84</td>
<td>High</td>
</tr>
<tr>
<td>Brief COPE: Problem Subscale</td>
<td>6</td>
<td>0.86</td>
<td>High</td>
</tr>
<tr>
<td>Pearlin Mastery Scale</td>
<td>7</td>
<td>0.64</td>
<td>Medium</td>
</tr>
<tr>
<td>Extraversion</td>
<td>4</td>
<td>0.389*</td>
<td>Low</td>
</tr>
<tr>
<td>Self-disclosure</td>
<td>3</td>
<td>0.84</td>
<td>High</td>
</tr>
<tr>
<td>Peer Similarity</td>
<td>6</td>
<td>0.88</td>
<td>High</td>
</tr>
<tr>
<td>Perceived Support Subscale of Quality of Relationships Inventory</td>
<td>7</td>
<td>0.92</td>
<td>High</td>
</tr>
</tbody>
</table>

*Deleting question #4 (“I prefer doing things along”) brings alpha up to 0.76. However, subsequent regression analyses were not affected by deleting this item.*
Appendix Q: Qualitative interview guide

Interview Guide

To interviewer:

Caring for an elderly parent can be an emotional experience. In turn, the following is a list of events/occurrences that require you to stop the interview. In addition to this list, use your discretion in assessing the circumstances that might indicate that a carer is feeling too pressured, uncomfortable or upset to continue the interview.

1. If a carer explicitly says to stop the interview
2. If the carer verbally or physically implies that they would like the interview to stop (i.e. a hand gesture of “stop”, saying “I don’t think I can do this”, etc…)
3. If the carer is crying to the point of being unable to speak

Upon stopping, ask the carer if they would like to reschedule the rest of the interview for a later date, if they feel they can continue after taking a short break, or if they would like to drop-out of the study.

To carers:

Throughout this interview I would like you to share your experiences of interacting with caregiving peers ___(online OR in person)__. I have a few questions to guide our discussion but feel free to elaborate on what is important to you or to bring up important experiences that my questions may not capture. Please remember that you can share as much or as little as you like

1. Can you please start by describing your caregiving situation
   Probes:
   a. Who you’re caring for (mom or dad) and why
   b. What does your parent have difficulty doing?
   c. What do you help your parent with?
   d. How did you become the carer?
   e. How did you feel about becoming a carer for your parent?
   f. What would a typical day have looked like for you prior to becoming a carer? What does a typical day look like now?

2. Throughout your caregiving experience, what have you felt you needed support with?
   Probes:

3. Who have you received support from? For what?
   Probes:
   
   Now I’d like to learn a bit more about your interaction with other carers. For the rest of this interview, I will refer to other carers as your peers.

4. Could you describe your experiences with interacting with your peers
   Probes:
   a. How have you been interacting with other carers?
   b. How long have you been interacting with other carers?
   c. What type of support (e.g. emotional, informational) have you been receiving from other carers?
   d. How have you felt, overall, about the received you’ve received from other carers?

   Now I’d like to learn a little bit more about your relationship with specific peers. If you remember, you answered the online survey based on your peer with the initials ______.

5. Could you tell me a little bit about the history of the relationship with this peer?
   Probes:
   a. How did you meet?
   b. How long have you been interacting?
   c. How often do you interact?
   d. What type of support do you receive from this peer?

6. Could you tell me about the quality of your relationship with this peer?
   Probes:
   a. How close are you with this peer?
   b. How would you describe the sharing of advice with this peer?
   c. Do you confide in this peer? What type of information do you share?
   d. How does this peer assist you, if at all?

7. Would you say that you are similar or dissimilar to this peer? How so?
   Probes:
   a. Demographics?
   b. Caregiving experience?
   c. Personality?
   d. Hobbies?
   e. Emotions and mental state?
   f. Life outlook?
8. Has being similar/dissimilar to this peer affected your relationship? If so, how? If not, why not?
   Probes:
   a. How has it affected the amount and duration of contact?
   b. How has it affected the strength of your ties?

9. Could you please describe the support you have received from this peer?

10. How has this support made you feel?

11. What role do you think the quality of your relationship with this peer has played?
   Probes:
   a. Has it impacted your ability to count on this peer?
   b. Has it impacted the time you spend with this peer?
   c. Has it impacted the help you receive from this peer?
   d. Has it impacted the feedback you receive from this peer?
   e. Has it impacted the advice you receive from this peer?

Now I’d like to learn a little bit about how you feel about interacting with this peer _____
   (online or in person)

12. How have you found this mode of interaction?
   a. Things you like/dislike about it?
   b. Why you choose this mode versus another

13. How has interacting ____(online/in person)____ affected the support you receive from this peer?
   a. Has it made it easier/harder to receive support? How so?
   b. Has it affected the type of support you receive? Please explain.
   c. Has it affected how supported you feel by this peer? How so?

14. Has interacting ____ (online/in person)____ affected your ability to identify similarities between you and this peer? If yes: How so?; If no: Why do you think that is?
   a. Has it made it easier/harder? How so?

15. How has interacting ____ (online/in person)____ affected the quality of your relationship with this peer? If yes: How so?; If no: Why do you think that is?
   a. How close are you with this peer?
   b. Do you confide in this peer? What type of information?
   c. How does this peer assist you, if at all?
   d. Do you ask this peer for advice?
16. How has interacting ___(online/ in person)___ affected how supported you feel by this peer? If yes: How so? ; If no: Why do you think that is?
   a. Has it impacted your ability to count on this peer?
   b. Has it impacted the time you spend with this peer?
   c. Has it impacted the help you receive from this peer?
   d. Has it impacted the feedback you receive from this peer?
   e. Has it impacted the advice you receive from this peer?
Appendix R: Assumptions of Regression Analysis

Relationship between independent variables

- Assumption 1- Independence of residuals: There was independence of residuals, as assessed by a Durbin-Watson statistic of 1.764 (2 is what is aimed for).
- Assumption 2- Linearity between independent variables and dependent variable: Partial regression plots demonstrated a linear relationship between all independent variables and the dependent variable (perceived support).
- Assumption 3- Homeoscedasticity: The studentized residuals were plotted against the unstandardized predicted values and the plot demonstrated a horizontal line of fit, suggesting homeoscedasticity.
- Assumption 4- Multicolinearity: A Pearson’s Correlation indicated that none of the independent variables were correlated ($r<0.7$). The collinearity statistics (Tolerance and VIF) also indicated that the independent variables were not collinear (All tolerance > 0.1 and all VIF < 10)

Unusual data points

- Assumption 5- Detecting outliers: Casewise diagnostics indicated all cases had standardized residuals less than ±3. By examining the studentized deleted residuals, we observed only one value that was slightly greater than ±3 (-3.18).
- Assumption 6- Checking for leverage points: By examining the leverage values, we observed 11 cases that were only slightly over the ‘safe’ 0.2 cut-off (Range: 0.206 to 0.399).

- Assumption 7- Checking for influential points: By examining Cook’s Distance values, we observed no values over 1 (i.e. no influential points).

**Normality of data**

- Assumption 8- The data are normally distributed: By observing the histogram and P-P Plot, we observed our data to be normally distributed.