When daughters become caregivers to a parent who has suffered a stroke: A qualitative exploration of how the parent-to-child relationship is associated with caregiver well being

by

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A thesis submitted in conformity with the requirements for the degree of MSc
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Abstract

Rationale: Many community-dwelling stroke survivors receive care from their family, often daughters. However, we lack in-depth information on the caregiver/care-recipient relationship and its impact on adult daughter caregivers (ADCs).

Objective: To systematically review the caregiving literature and qualitatively explore the pre-and post-stroke parent-to-child relationship and its association with ADCs’ well being.

Method: A qualitative descriptive methodology used in-depth interviews of 23 ADCs. Analyses generated themes.

Findings: Four themes were revealed: 1) The pre-stroke ADC-to-parent relationship is associated with the decision to take on the caregiving role; 2) Changes in the parent-to-child relationship occur as a result of providing care; 3) Changes to an ADC’s relationships with others arises from providing care to a parent and 4) Changes to caregiver lifestyle, outlook and physical and emotional well being arise from caregiving.

Conclusion: There is a need for interventions that focus on role strains and issues related to relationship loss.
Acknowledgements

First and foremost, I would like to extend my sincerest gratitude to my supervisor, Dr. Jill Cameron. I still remember being stunned that you responded so quickly to my email asking you to take me on as your student. Since then you have never ceased to encourage and support my ideas and I have been nothing less than fortunate to have had you as an advocate of my research. I look forward to your mentorship in the future and hope to be half the researcher you are one day! To my Program Advisory Committee members, Dr. Moira Kapral and Dr. Monique Gignac, I thank you both for your enthusiasm about my project and for all the feedback you have provided.

To the Family Lab team – I don’t know how I would have gotten through this final stretch without you guys! Marco, Anna, Linda, Emily, Victrine and our latest addition, Sam – you guys kept me laughing and having fun even when my thesis was determined to bring me down. To my peers and good friends Bimal and Sabrina, thank you guys for bearing through my moments of panic, for providing insight from your own experiences and for doing it all with the perfect mix of cruelty, sarcasm and good intention.

I am fairly certain that I wouldn’t be anywhere near where I am today without the support of my family. To my parents Manal and Adel, thank you for not being horrified when I decided I didn’t want to go to medical school and for supporting my research even when you weren’t quite sure what it was about. Thanks to John for giving me something other than the writing process to loathe (and for actually being a pretty great brother). Thanks to Teta and Nonos who I imagine have spent the majority of the last few months praying for my success—it is appreciated and I’m thankful that God listened. Last but not least, a big thank you to Mike who regularly gives me the freedom to be the science nerd that I am. Your understanding, wisdom and comical graphs keep me going.

Finally, I would like to thank the adult daughter caregivers who took time out of their already busy lives to share their experiences with me and to Toronto Rehab Institute, St. John’s Rehab Hospital, West Park Health Care, The Aphasia Institute and the March of Dimes for helping us connect.
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CHAPTER ONE

Systematic review:
“What Factors are associated with Adult Children Caregivers’ (ACC) Well Being?”
**Abstract**

**Rationale:** Currently, 15% of the Canadian population is 65 years and older, which is similar to figures reported in the United States (12.8%) and Europe (17.1%). As Canadians age, they may experience a range of physical and cognitive disabilities, requiring care from others, often family members. Although many studies have examined the impact of caregiving on a caregivers’ well being, less is known about ways that the previous parent-to-child relationship may affect the caregiving role and adult children caregivers’ (ACCs) well being.

**Objective:** This systematic review examined the factors associated with ACC well being and assessed the methodological strength of studies in this area.

**Methodology:** A systematic search of Medline, Psycinfo, EMBASE and CINAHL databases (1996-July, 2011) was performed using a structured search strategy and inclusion/exclusion criteria were applied.

**Results:** The literature search identified 683 original, peer-reviewed studies published in English with only 50 meeting the inclusion criteria. Most of the studies were not illness-specific. The type of impairment experienced by the parent affected ACC well being, with cognitive impairments increasing burden and decreasing life satisfaction. A range of factors moderated this relationship, including the quality of the parent-to-child relationships and support received. Inconsistent findings were reported regarding the influence of culture, filial obligation and income on well being.

**Conclusions:** Future studies would benefit from examining the nature of the parent-to-child relationship and perceived changes in the relationship related to caregiving in order
to better understand caregiver well being. Since studies lack measures to assess this facet of the caregiving context, future studies would also benefit from employing a qualitative methodology to gain a more in-depth understanding of the perceived changes.
1. Introduction

North America and Europe are presently experiencing a demographic shift towards an aging population. Currently, 15% of the Canadian population is 65 years and older (1). The United States and Europe are similar, with those aged 65 or more comprising 12.8% and 17.1% of the population, respectively (2;3). With the Baby Boomer generation reaching retirement age, this percentage will rise to nearly 20% in both Canada and the U.S. by 2030 (1;2) and to nearly 40% in Europe (3). In a review of the literature, Crimmins and Beltran-Sanchez report that those under, but approaching 65 years of age (i.e. aging Baby Boomers), are experiencing an increase in disability and functional limitations (4).

As individuals age, they may experience limitations in their ability to perform activities of daily living (ADLs) (e.g. bathing, dressing) as well as in instrumental activities of daily living (IADLs) (e.g. driving, paying bills) (5). In fact, the 2006 prevalence of disability in Canada was 44.7% for those 65 years and older (6). In some cases, these disabled individuals may require assistance from others to help with the management of their limitations. Currently, the majority of the care that community residing elderly Canadians and Americans receive as a result of functional limitations is provided by family members. In 2007, the unpaid care provided by family caregivers in Canada was estimated to save the healthcare system $25 billion (7). With ten times the population of Canada, this amount was a striking $350 billion in the U.S. in 2006 (8). 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 caregivers often experience a restriction in their social functioning (9;10) and a decrease in their overall quality of life (11). A systematic review of the literature concluded that caregivers are at heightened risk for poorer physical and mental health as compared to their non-caregiving counterparts (12). The increased psychological stress experienced by caregivers often results in earlier institutionalization of the care recipient (13). This is highlighted by Spillman and Long’s (14) finding that reducing the physical and financial stresses that caregivers experience decreases the risk of admission of the cared-for to long-term care facilities. Since it appears that caregivers with better physical and mental well-being are better able to provide higher quality home care over a longer period of time (15), supporting families so that they can sustain their caregiving role is crucial. For this reason, understanding ways to improve caregiver well being has been and continues to be a research priority.

Systematic reviews of the caregiving literature have been published in the fields of cancer, dementia, stroke and other illness populations. These reviews have summarized the literature on various aspects of the caregiving experience including caregiver needs (16;17), caregiving outcomes (18-20) and the benefits of caregiver interventions (21;22). With regard to caregiving outcomes, several systematic reviews have focused on summarizing and appraising the body of literature that investigates factors associated with caregiver well being. Greenwood et al’s (18) systematic review of the qualitative literature pertaining to caregivers of stroke survivors revealed that stroke carers reported at least one emotional response to caregiving (e.g. distress, managing emotional responses, feeling under-valued). Greenwood et al (19) also performed a similar review of the quantitative literature which revealed that the most
commonly studied outcome was emotional well being. Other outcomes included burden, quality of life and stress (19). Caregivers’ psychological characteristics (e.g. mastery, coping) and stroke survivor limitations (e.g. extent of physical and cognitive limitation) had the most significant impact on caregiver well being. This latter finding is in line with Black et al’s (20) systematic review of dementia caregivers, where half of the included studies found the behavioural and psychological symptoms of dementia to be the strongest correlate of caregiver burden. It also corresponds to the finding from Pinquart et al’s (23) systematic review of dementia caregivers that the care recipient’s physical impairments and behaviour problems are more strongly associated with low subjective well being than the intensity of caregiving (i.e., amount of care provided). The systematic review by McKeown et al (17) of multiple sclerosis (MS) caregivers showed that MS caregivers report deficits in physical health, most commonly arthritis, and detriments to their psychological well being (e.g. being in a state of constant sorrow, stress).

These systematic reviews have found both methodological strengths and limitations in the caregiving literature. Greenwood et al (18) noted that the qualitative studies they reviewed provided information about the roles and relationships that are relevant to stroke caregivers and that are associated with their well being. These two facets of the caregiving experience were noted to be missed by quantitative studies (18). Additionally, they commented that qualitative studies contributed to increasing the breadth of caregiving experiences captured by studies (18). In their review of the quantitative stroke caregiving literature, Greenwood et al (19) pointed out that since 35% of the studies included in their review were longitudinal, this contributed to the
understanding of evolutions in caregiving outcomes. Despite these positive contributions to the literature, the systematic reviews also identified areas for improvement. Greenwood et al (18) noted that qualitative studies needed to improve their reporting of data collection timing post-stroke and pay greater attention to the implications of telephone versus in-person interviewing. For the quantitative studies, Greenwood et al (19) suggested that studies provide a more rigorous definition of ‘caregiver’ since the failure to specify makes generalizing caregiver experiences and needs difficult. Black et al (20) explained that a substantial body of knowledge now existed using cross-sectional studies to investigate the association between the behavioural and psychological symptoms of dementia (BPSD) and caregiving outcomes such as depression and burden. They recommended that future research focus on longitudinal designs with cohorts to assess changes over time. Finally, McKeown et al (17) commented that the multiple sclerosis caregiving literature was limited by the use of small sample sizes and the lack of reliable and validated disease-specific assessment tools.

In the past, studies have focused largely on spousal caregivers of the aging population (24-26). The current demographic trend, however, indicates that adult children will increasingly become primary caregivers to aging parents. In fact, a recent 2007 National Canadian Survey revealed that 62% of caregivers over 45 years old were adult children (1). A similar 2009 National Survey conducted in the U.S. showed that 44% of the caregiving population aged 18 and older was comprised of adult children (27). Adult children are often 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 may introduce an added pressure to the adult children’s lives, which may have
important implications for their well being. Furthermore, the provision of care by children is unique in that the nature of their relationship with a parent was, at one time, a period of dependence on the parent who, for much of the child’s life, would have been viewed as an authority figure who provided nurturing and resources. Upon becoming the caregiver, a role reversal occurs in as far as the parent becomes dependent on the child as the child provides them with assistance and support. This role reversal may have important implications for well being. Several studies exist in the literature that focus on this unique caregiving population and the correlates of their well being. To date, however, no systematic reviews have summarized and appraised this body of literature. Given that systematic reviews play an important role in informing future research and translating knowledge into practice (28,29), summarizing and appraising the literature focused on adult children caregivers’ (ACCs) well being may help to identify gaps in the literature that future studies can address and contribute to better clinical practices that support ACCs.

Consequently, the objective of this systematic review was to identify factors that have been associated with the health and well being of adult children who are caring for a parent and the relative importance or consistency of these factors across different research studies.

2. Methods

We performed a search of Psycinfo, EMBASE, Medline and CINAHL in July, 2011. The search strategy was tailored to each database using key terms that included: ‘caregiver’, ‘adult children’, ‘son’, ‘daughter’, ‘well-being’, ‘stress’, ‘depression’, ‘burden’, ‘adult-child relations’ and ‘caregiving’. These searches produced 1,315 studies
for consideration. After duplicates, non-English studies and non-peer reviewed studies were eliminated, 683 studies remained. I then subjected these studies to the inclusion and exclusion criteria. If it was not clear whether a study met the inclusion criteria, my supervisor (Dr. Jill Cameron) reviewed it.

2.1. Inclusion criteria

Studies were included if: 1) the sample comprised of at least 50% adult children caregivers; 2) outcomes reflected adult children caregivers’ health or well being (e.g., physical health, mental health, life satisfaction or burden); and 3) observational study that employed either quantitative or qualitative methods in order to capture a breadth of outcomes research.

2.2. Exclusion criteria

Studies were excluded if: 1) they consisted of caregivers to institutionalized parents; 2) focused on palliative caregiving; 3) evaluated an intervention; or 4) evaluated clinical or research measurement tools.

2.3. Data Collection from Studies

A data extraction form was designed to obtain the following information from each study: 1) study objectives; 2) theoretical perspectives that influenced the research question and analysis; 3) caregiving population (e.g., gender distribution, type and amount of care provided); 4) care-recipient population; 5) data collected and 6) findings: a) significant and non-significant findings in the case of quantitative studies or b) key themes of qualitative studies.
2.4. Methodological Rigor of the Studies

Quality assessments of research methods and findings are a recommended feature of reviews since they afford clinicians the opportunity to make informed practice decisions based on the quality of evidence presented (19;30). Furthermore, they help to inform future research endeavours by identifying limitations in existing study design or gaps in methodological approaches. As Mallen et al (30) have discussed, however, there is no standard quality assessment tool for observational studies despite the standard use of assessment tools in the randomized control trial (RCT) literature. As a result, systematic reviews of observational studies rarely include an assessment of methodological rigor (30). For the current review, we generated an assessment tool that drew from several sources to include features discussed as important for the methodology of caregiving studies (19). The assessment tool corresponded with well-established assessment tools such as those used in RCTs (i.e. PEDRO (www.pedro.org), STROBE (www.strobe-statement.org)) that consider methodological elements including the study features, study conduct and results (31-34). In addition, a recent review of the caregiving literature by Greenwood et al (19) noted that many studies failed to provide a definition of ‘caregiver’. Consequently, this element was also incorporated into our assessment. Quantitative studies could be assigned a minimum score of 0 and a maximum score of 12. The specific items can be found in Table 1.1. I used the assessment tool to generate a score out of 12 for each of the 50 studies. My supervisor, Dr. Jill Cameron, rated a subset of 10 studies in order for us to perform a test of inter-rater reliability (i.e. the degree to which our ratings corresponded). After this test, I revisited the 50 studies and performed a second round of methodological quality scoring.
Table 1.1 –Methodological Assessment Tool for Quantitative Studies

<table>
<thead>
<tr>
<th>Methodological Elements</th>
<th>Design Features</th>
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<tbody>
<tr>
<td><strong>Methodology</strong></td>
<td></td>
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<tr>
<td>1. Hypothesis/hypotheses made explicit</td>
<td></td>
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<tr>
<td>2. Type of study made clear</td>
<td></td>
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<tr>
<td>3. Inclusion/exclusion criteria made explicit</td>
<td></td>
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<tr>
<td>4. Definition of carer/caregiver provided</td>
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<tr>
<td>5. Specifies care recipient population (e.g. illness they suffer from) and needs (e.g. ADL or IADL)</td>
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<td>6. Outcomes and other variables described (e.g. confounding, independent)</td>
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<tr>
<td>7. Sample size justified</td>
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<tr>
<td><strong>Study Conduct</strong></td>
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<tr>
<td>8. Response rate (completers) described</td>
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<tr>
<td>9. Participants representative of population (i.e. not convenience sampling)</td>
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<tr>
<td>10. Statistical analysis addressed study objectives</td>
<td></td>
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<tr>
<td><strong>Results</strong></td>
<td></td>
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<tr>
<td>11. Participant characteristics described</td>
<td></td>
</tr>
<tr>
<td>12. Numerical description of outcomes given (e.g. p-values, medians/means, standard deviation)</td>
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Though scoring the methodological strength of quantitative studies is commonplace (i.e. RCTs), there is some concern that qualitative studies should be evaluated differently (e.g. assessing quality without quantifying it) (35;36). We assessed qualitative studies using the Critical Appraisal Skills Programme’s (CASP) “10 questions to help you make sense of qualitative research” (http://www.sph.nhs.uk/sph-files/casp-appraisal-tools/Qualitative%20Appraisal%20Tool.pdf). The CASP’s qualitative method assessment requires reviewers to evaluate and report on whether the study adheres to basic principles of qualitative research in a systematic way, but does not generate a ‘score’ representing the study’s quality (37). Consequently, unlike quantitative method
assessment, qualitative design considerations were not scored based on ‘yes or no’ questions. Rather, using the CASP, we were able to consider elements such as: 1) the appropriateness of using a qualitative design (e.g. is an open-ended exploration of a phenomena and the generation of themes appropriate for the study objectives?); 2) the data collection process; 3) the report of ethical considerations (e.g. ethical board review process and consenting process); 4) the rigor of the analysis (e.g. in-depth description of analysis process); and 5) the clarity with which findings are presented (e.g. sufficient data presented to support findings, discussion of how findings relate to original research objectives). In keeping with qualitative tradition, this allowed us to discuss the appropriateness of the study design and the degree to which the authors effectively employed qualitative principles (e.g. thematic analysis, reflexivity) without quantifying the strength or weakness of the methodology.

3. Results

After applying the inclusion and exclusion criteria, the search resulted in the inclusion of 44 studies. Further review of the studies’ reference lists resulted in the addition of 6 new studies for a total of 50 studies reviewed (see: Figure 1.1). A summary of the studies can be found in Table 1.2.
Figure 1.1 – Search Strategy (ACC= Adult child caregiver)

- Literature search: 1,315
- 1st screen: 683
  - Duplicates: n= 188
  - Non-peer reviewed: n= 383
  - Non-English: n=61
- Did not meet inclusion criteria:
  - End of life: n=13
  - Parent Institutionalized: n=19
  - Non-investigational (e.g. review, method study): n=88
  - Interventionsal: n= 23
  - Non-ACC: 357
  - Non-ACC well being: n= 139

- Included from search: n= 44
- Additions from reference search: n= 6
- Included in study: n= 50
Table 1.2 – Summary chart of studies investigating the factors associated with the well-being of adult child caregivers (ACCs)  
[Caregiver = CG]

<table>
<thead>
<tr>
<th>Method</th>
<th>Author (Year of publication)</th>
<th>Objective</th>
<th>Sample [caregiver and care-recipient population]</th>
<th>Health and well being outcomes (measurement instrument)</th>
<th>Key findings</th>
</tr>
</thead>
</table>
| 7 | Albert et al (1996)  
Cross-sectional | To explore the relationship of viewing parent care as similar to child care on burden and satisfaction | - 426 adult daughters  
- Care-recipient population: general aging | - Burden (multi-item scale)  
- Satisfaction (multi-item scale) | - 60% agreed that parent care is like child care; 12% strongly agreed  
- Holding this view was associated with greater report of burden and lower satisfaction |
Cross-sectional | To examine the association of role stress and dispositional optimism on psychological well being of women who possess multiple roles | - 296 adult daughters  
- Care-recipient population: general aging | - Depression (CES-D)  
- Life satisfaction (multi-item scale) | - Optimism moderates the negative effects of marital stress on psychological well being  
- Optimism didn’t moderate stress from other roles  
- Optimism directly relates to reduced depressive symptomatology  
- High optimism associated with greater life satisfaction |
<table>
<thead>
<tr>
<th>Method Quality Rating for quantitative studies [max. 12]</th>
<th>Author (Year of publication)</th>
<th>Objective</th>
<th>Sample [caregiver and care-recipient population]</th>
<th>Health and well being outcomes (measurement instrument)</th>
<th>Key findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>Bookwala et al (2009) Longitudinal</td>
<td>To evaluate the long-term impact of providing care to an ill or disabled parent</td>
<td>119 recent caregivers - 63 experienced caregivers - 106 former caregivers - 428 non-caregivers - Daughters and sons (distribution unspecified) - Care-recipient population: general aging</td>
<td>Depression (CES-D) - Life-satisfaction (multi-item scale)</td>
<td>- Experienced son caregivers showed decline in depressive symptoms over time - Experienced daughter caregivers reported greater depressive symptoms at T3 than sons - Recent and experienced daughter caregivers experienced increase in long-term depression from T2 to T3</td>
</tr>
<tr>
<td>Method Quality Rating for quantitative studies [max. 12]</td>
<td>Author (Year of publication)</td>
<td>Objective</td>
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<td>Health and well being outcomes (measurement instrument)</td>
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<td>9</td>
<td>Carpenter (2001) Cross-sectional</td>
<td>To examine the relationship between attachment dimensions and the nature of care that adult daughters provide to their mothers and the association with daughters’ well being</td>
<td>- 80 adult daughters - Care-recipient population: general aging</td>
<td>- Burden (multi-item scale)</td>
<td>- Greater attachment associated with lower burden</td>
</tr>
<tr>
<td>8</td>
<td>Carruth et al (1996) Cross-sectional</td>
<td>To explore the extent to which positive/negative exchanges, family functioning, reciprocity, caregiver satisfaction and caregiver well being are associated with each other</td>
<td>- 140 daughters; 31 sons - Care-recipient population: general aging</td>
<td>- Family function (family adaptability and cohesion evaluation scales) - Satisfaction (family satisfaction scale) - Reciprocity (caregiver reciprocity scale) - Exchange types (caregiver exchange index) - Emotional well being (revised multiple affect adjective check list)</td>
<td>- Receipt of positive exchanges was directly and indirectly associated with all variables (except family functioning and love/affection) - When caregivers receive positive exchanges from parents they report emotionally satisfying relationships and less caregiver strain</td>
</tr>
<tr>
<td>Method Quality Rating for quantitative studies [max. 12]</td>
<td>Author (Year of publication)</td>
<td>Objective</td>
<td>Sample [caregiver and care-recipient population]</td>
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</tbody>
</table>
| 10                                                      | Christensen et al (1998)      | Cross-sectional To examine how mastery in caregivers' additional roles relates to well being | - 296 adult daughters  
- Care-recipient population: general aging | - Mastery (multi-item scale)  
- Depression (CES-D)  
- Live satisfaction (multi-item scale)  
- Dispositional Optimism (Life Orientation Test) | - Mastery in family roles associated with well being but not mastery in employee role  
- Greater well being associated with mastery in many roles  
- High mastery in parent care and marital roles associated with lower depression and higher life satisfaction |
| 8                                                       | Coe et al (2009)              | Longitudinal To test whether caregiving has adverse effects on ACC mental and physical health | - 700 married females  
- 204 single females  
- 480 married males  
- 83 single males  
- Care-recipient population: general aging | - Mental health (CES-D)  
- Physical health (multi-item scale) | - Depression symptoms are persistent for women (i.e. significant after 2 years)  
- Married women experience a small but significant decrease in the likelihood of being in very good or excellent health 2 years into caregiving |
<table>
<thead>
<tr>
<th>Method Quality Rating for quantitative studies [max. 12]</th>
<th>Author (Year of publication)</th>
<th>Objective</th>
<th>Sample [caregiver and care-recipient population]</th>
<th>Health and well being outcomes (measurement instrument)</th>
<th>Key findings</th>
</tr>
</thead>
</table>
| 10                                                       | Dautzenberg et al (1999)     | Longitudinal | To examine how holding multiple roles relates to distress levels and role strain experienced by middle-aged women | - Caregiver role strain (multi-item scale)  
- Care-recipient population: general aging  
- Distress (Lagner Scale: 6 items) | - Caregiving role not associated with higher levels of distress  
- Caregiving role commitment didn’t moderate effect of caregiving on distress  
- Number of roles held was not associated with distress |
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<tr>
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<tr>
<td>8</td>
<td>England (1996) Cross-sectional</td>
<td>To explore the relationship between ‘sense of relatedness’, perceived health and ACCs’ interface with an interpersonal network in the presence and absence of crisis</td>
<td>- 128 daughter caregivers - 40 son caregivers - Care-recipient population: dementia</td>
<td>- Perceived health (1 item) - Emotional arousal (multi-item scale)</td>
<td>- Higher likelihood of interfacing with a personal network was associated with a higher rating of perceived health - Lower likelihood of interfacing with a personal network was associated with greater emotional arousal - The more ACCs interfaced with an interpersonal network in the absence of crisis, the more likely they were to report a greater sense of well being (not the case in the presence of crisis)</td>
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| 10                                                     | Franks et al (1996)          | To investigate the relationship of personal and secondary emotional and instrumental support on caregivers’ well being | - 126 daughter caregivers  
- Care-recipient population: general aging | - Caregiving stress (multi-item scale)  
- Physical health (multi-item scale)  
- Depression (CES-D)  
- Positive affect (Bradburn affect scale)  
- Marital satisfaction (Quality of Marriage Index)  
- Dispositional optimism (Life Orientation Test) | - Support had no buffering interaction with positive affect  
- All types of support had a main effect on marital satisfaction  
- No significant relationship of support on depression  
- Instrumental support buffered relationship between stress and physical health  
- Optimism suppressed relationship among stress, support and well being |
| 8                                                      | Gonyea et al (2008)          | To investigate the relationship of guilt on caregivers’ psychological well being | - 66 daughter caregivers  
- Care-recipient population: general aging | - Burden (measured through analysis of participants’ response to question ‘did you feel that caregiving was a burden’  
- Burden intensity (multi-item scale) | - Significant portion of caregiver burden explained by feelings of guilt  
- Intensity of burden associated with emotional toll of the caregiving experience |
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<td>n/a</td>
<td>Grand et al (1999) Qualitative</td>
<td>To examine negotiation processes involved in setting up and developing a caregiving relationship in order to understand caregivers’ expressions of stress</td>
<td>- 22 daughter caregivers - 7 son caregivers - 7 daughter-in-law caregivers - Care-recipient population: general aging</td>
<td>- Interviews asked CGs to reconstitute: biographies, relationships history and impact of disability on this history - Caregiver stress was also investigated</td>
<td>- When ACCs did not acknowledge a debt to their parents or grief over the past relationship is expressed, their burden is more intense - When care-recipient doesn’t acknowledge assistance, ACCs experienced grief - Spousal support increased caregiving tolerance</td>
</tr>
<tr>
<td>n/a</td>
<td>Jolicoeur et al (2002) Qualitative</td>
<td>To explore the dynamics of caregiving in Mexican-American families and differences between highly acculturated and less acculturated caregivers</td>
<td>- 39 daughter caregivers (22 acculturated; 17 cultured) - Care-recipient population: general aging</td>
<td>- Structured and open-ended interview questions asked about the typical dimensions of caregiving to allow respondents to describe their experiences using their own terms</td>
<td>- The cultured group reported that their health had worsened more often than acculturated group - Cultured group was more burdened due to less social support and greater role conflict</td>
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<td>11</td>
<td>Kang (2006) Cross-sectional</td>
<td>To understand how strain from the caregiving role differs for spouse and child caregivers</td>
<td>- 268 spouse caregivers  - 386 daughter caregivers  - 129 son caregivers  - Care-recipient population: general aging</td>
<td>- Self-rated health (multi-item scale) - Caregiver perceived overload (multi-item scale)</td>
<td>- Elder’s level of cognitive impairment not related to emotional strain  - Moderate correlation between elder’s disruptive behaviours and caregivers’ perceived overload</td>
</tr>
<tr>
<td>9</td>
<td>Karantzas et al (2010) Cross-sectional</td>
<td>To examine the role of attachment orientations (i.e. anxiety and avoidance) in caregiving situations</td>
<td>- 119 ACCs (40 son caregivers; 79 daughter caregivers) - Care-recipient population: general aging</td>
<td>- Carer burden (50-item inventory)</td>
<td>- Avoidance positively related to burden and negatively related to willingness to provide future care  - Attachment anxiety was unrelated to adult children’s current and future caregiving</td>
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<td>9</td>
<td>Kim et al (2003) Cross-sectional</td>
<td>To discover the predictors of Korean daughter and daughter-in-law (DIL) caregivers’ health while caring for a cognitively impaired elder</td>
<td>- 120 CG (93 DIL; 27 daughters) - Care-recipient population: general aging</td>
<td>- Depression (CES-D) - Physical Health (Multilevel Assessment Inventory) - Effects of non-cultural variables on CG's health outcomes outweigh those of cultural variables - Cognitive impairment predicts caregiver depression</td>
<td>- Cognitive impairment predicts CG depression - Of the cultural variables, only social conflict was a significant predictor of depression</td>
</tr>
<tr>
<td>11</td>
<td>Kim et al (2008) Longitudinal</td>
<td>To examine the effect of caregiver psychological distress and care-recipient psychological distress on ACC quality of life</td>
<td>- 98 mother-ACC dyads included - Care-recipient population: cancer</td>
<td>- Quality of Life (Medical outcomes study (MOS) SF-36 or SF-12) - Psychological distress (Profile of mood states)</td>
<td>- ACCs’ own level of psychological distress was the strongest predictor of their quality of life</td>
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| 11                                                      | Lawrence (1998) Cross-sectional | To examine the path by which relationship quality alters the associations between the various components of the stress process | - 118 CGs (73% ACC and 23% spouses)  
- 69% of caregivers were women  
- Care-recipient population: general aging | - Perceived overload (multi-item scale)  
- Perceived role captivity (multi-item scale)  
- Depression (CES-D) | - Presence of problem behaviors was significant related to higher levels of perceived overload, role captivity and depression  
- Cog impairment not significantly related to quality of relationship or any of the outcome variables  
- Higher levels of relationship quality were related to lower levels of depression |
| 10                                                      | Lee et al (1998) Cross-sectional | To examine the relationship of culture-specific factors on caregivers’ burden | - 107 ACCs (gender distribution not specified)  
- Care-recipient population: general aging | - Burden (Burden Interview)  
- Health status (1-item)  
- Gratification (1-item) | - Lower level of burden among Koreans was associated with filial responsibility |
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<td>Lee et al (2010)</td>
<td>To investigate factors related to the caregiving appraisal of people who care for older stroke patients in Korea</td>
<td>- 242 caregivers (125 ACCs- 21 sons, 104 daughters)</td>
<td>- Caregiving appraisal (27 item Revised Korean Caregiving Appraisal Scale)</td>
<td>- Appraisal scores did not differ by gender, education or income - Caregivers who resided in urban areas reported higher scores of caregiving appraisal (i.e. more stressed) compared to those who resided in rural areas</td>
</tr>
<tr>
<td>11</td>
<td>Li et al (1997)</td>
<td>To explore the fit between the personal context in which stress is experienced and the type of support received by female caregivers</td>
<td>- 103 wife caregivers and 149 daughter caregivers</td>
<td>- Caregiver stress (Barthel Index) - Depressive symptoms (CES-D)</td>
<td>- Participating in social activities was associated with lower levels of depression for daughters - Emotional support had a buffering effect on stress for daughter and wife caregivers</td>
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| 11                                                     | Li et al (1999) Longitudinal | To discover the extent to which daughter caregivers manifest changes in depressive symptoms over an 18-month period | - 115 daughter caregivers  
- Care-recipient population: general aging | - Depressive symptoms (CES-D)  
- Global feelings of mastery (Environmental Mastery Scale) | - Educated ADCs more likely to use problem-focused coping  
- Greater number of parental behavior problems associated with lower level of mastery  
- Depression increased for 11 daughters over time and decreased for 6 |
| 11                                                     | Li et al (2003) Longitudinal | To explore how caregiving affects child-to-parent relationship quality for daughter providing care to a parent and to discover whether relationship quality is associated with caregiver depression | - 196 daughter caregivers  
(70 caring for parent with cognitive and physical deficits; 36 for physical only; 57 non-caregivers)  
- Care-recipient population: general aging | - Relationship quality (Positive Affect Index)  
- Depressive symptoms (CES-D)  
- Self-esteem (Rosenberg Self-esteem Scale) | - Daughters caring for parents both physical and cognitive impairments have poorer and deteriorating relationships with parents as compared to non-caregiving daughters  
- Association between relationship quality and depressive symptoms is mediated daughters' self-esteem |
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<td>11</td>
<td>Li et al (2005)</td>
<td>Cross-sectional</td>
<td>To investigate: a) whether the quality of the daughter-to-parent relationship in the caregiving context is associated with the self-esteem of daughter caregivers and b) whether the salience of the daughter role moderates the association between relationship quality and self-esteem</td>
<td>- Relationship strain (Zarit Burden Interview) - Self-esteem (Rosenberg Self-esteem Scale)</td>
<td>- Daughters feel more positively than negatively about relationships (i.e. high closeness, low strain) - Relationship quality correlated with self-esteem of daughters - Relationship strain was negatively associated with on daughters' self-esteem</td>
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<td>7</td>
<td>Magai et al (1998) Cross-sectional</td>
<td>To explore the relationship of attachment style and emotion regulation in dementia to caregiver burden</td>
<td>- 168 caregivers (23% spouses; 54% adult children- gender distribution unspecified) - Care-recipient population: dementia</td>
<td>- Caregiver burden (Zarit Burden Index)</td>
<td>- Burden lowest for those caregivers with secure pre-morbid attachment styles (as compared to those with avoidant and ambivalent pre-morbid styles) - Attachment style more potent predictor of burden than patient behavioural symptomatology</td>
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<td>9</td>
<td>Marks et al (2008)</td>
<td>To examine potential psychosocial moderators that might decrease well being effects of transitioning in the role of filial caregiver among adults with sole surviving parents</td>
<td>- 1060 ACCs (614 daughters; 446 sons)</td>
<td>- Depression (CES-D)</td>
<td>- Being employed while caregiving associated with higher depression for daughters than for sons</td>
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<tr>
<td></td>
<td>Longitudinal</td>
<td>- Care-recipient population: general aging</td>
<td>- Negative psychological well being (multi-item hostility scale)</td>
<td>- Positive psychological well being (multi-item scale)</td>
<td>- Not being married was associated with depression for sons more so than daughters</td>
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<td>- Positive affect (1 item)</td>
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<td>- Daughters reporting low relationship quality prior to caregiving reported greater declines in self-esteem over time than those with high quality pre-caregiving relationships</td>
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<td>- Less filial obligation associated with decreased physical health and happiness for daughters and higher psychological wellness for sons</td>
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<td>- Low education correlated with better psychological well being for daughters</td>
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| 10                                                       | Martire et al (1997)          | To examine changes in social as well as psychological well being over time as a function of a woman’s feelings of adequacy in each of her multiple roles | - 75 daughter caregivers  
- Care-recipient population: general aging | - Positive and affect (multi-item scale)  
- Marital satisfaction (multi-item scale) | - Those daughters who felt more adequate as mothers experiences less negative affect  
- Feelings of adequacy in spouse role related to better social well being and adequacy in mother role was associated with less negative affect |
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| 9                                                       | Mastrian et al (1996)         | Cross-sectional | To identify patterns in informal caregiving situations that are likely to lead to caregivers' perceptions that their health is affected negatively | - 75 spouse caregivers  
- 105 ACCs (gender distribution not specified)  
- Care-recipient population: general aging | - Social/recreational health strain (multi-item scale)  
- Physical health strain (multi-item scale)  
- Emotional health strain (multi-item scale) | - Cognitive impairment of elder was a positive predictor of health strain  
- Perception of social support was negatively associated with all types of health strain  
- Physical and cognitive impairments were significant predictors of social/recreational health strain  
- ACCs who spent a greater number of hours per week caregiving experienced more social/recreational health strain |
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| 8 Merz et al (2009) Panel                                | To investigate how intergenerational support provision and relationship quality relate to the wellbeing of the two generations | - 1456 child-parent dyads (60% of ACCs were daughters)  
- Care-recipient population: general aging | - Psychologic states (multi-item scale)  
- Overall life satisfaction (multi-item scale)  
- Health (1 question on how respondents assess health) | - Being married or cohabitating was positively related to wellbeing of both generations  
- Well being of ACC was associated with relationship quality  
- Higher penetration (instrumental support) was associated with lower well being  
- Quality of relationship positively associated well being when penetration was low; not correlation when penetration was high |
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<td>6</td>
<td>Mizuno et al (2005) Cross-sectional</td>
<td>To examine the impact of relocation by analyzing characteristics and factors that might contribute to caregivers' burden</td>
<td>- 133 daughter and daughter-in-law (DIL) caregivers - Care-recipient population: general aging</td>
<td>- CG burden (Japanese burden scale)</td>
<td>- Poor physical and sleeping status, inadequate support from other family members and lack of a person to consult on an informal basis were significant correlates of burden - Mental and physical status of parent and hours of elder care per day associated with perceived burden</td>
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<tr>
<td>10</td>
<td>Morana et al (2005) Cross-sectional</td>
<td>To better understand how the social and cultural expectation to care for one's parents might related to CG's perception of role captivity and ultimately impact both positive and negative indicators of well being</td>
<td>- 113 ACCs (23 sons; 90 daughters) - Care-recipient population: Alzheimer’s Disease</td>
<td>- Role captivity (Pearlin Scale) - Depression (CES-D) - Self-acceptance (SF Ryff and Keys Scale)</td>
<td>- Hispanic ACCs had significantly lower depression scores and higher self acceptance scores compared to non-Hispanic counterparts - Hispanic ACCs had significant lower levels of role captivity than non-Hispanic ACCs</td>
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<td>11</td>
<td>Noonan et al (1997) Cross-sectional</td>
<td>To examine the nature and level of association between meaning and well being in the caregiving situation</td>
<td>- 131 caregivers (55% ACCs – 53 daughters; 19 sons) - Care-recipient population: general aging</td>
<td>- Depression (CES-D) - Self-esteem (multi-item scale) - Loss of self (multi-item scale)</td>
<td>- Meaning in caregiving was negatively associated with the experience of depressive symptoms - Emotional support had the strongest association with self-esteem - Self-loss associated and burden associated with high frequency of care provided</td>
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<td>9</td>
<td>Raschick et al (2004) Cross-sectional</td>
<td>To explore the contribution of care-recipient helpfulness to caregiver costs and rewards</td>
<td>- 978 caregivers (412 daughters; 135 sons) - Care-recipient population: general aging</td>
<td>- Caregiver costs (multi-item scale) - Caregiver rewards (multi-item scale)</td>
<td>- ACCs reported greater rewards than spousal caregivers - Women reported greater costs than men - Sons did not report greater rewards than other caregivers</td>
</tr>
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<td>9</td>
<td>Raveis et al (1998) Cross-sectional</td>
<td>To examine the caregiving situation of adult daughters and to explore the impact of situational factors that may constrain or facilitate caregiving and the contribution of the caregiver’s appraisal of the caregiving situation</td>
<td>- 164 daughter caregivers - Care-recipient population: cancer</td>
<td>- Depressive symptoms (CES-D)</td>
<td>- Daughters’ level of depressive mood decreases with increased number of roles they possess - Greater sense of filial obligation was correlated with higher depressive symptomatology - Performing a greater variety of caregiving tasks was inversely correlated with depressive symptomatology</td>
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| 11                                                     | Raveis et al (2000) Panel   | To explore the determinants daughter caregivers’ levels of anxiety while caring for a parent with cancer | - 175 patient-daughter dyads  
- Care-recipient population: cancer | - Burden (multi-item scales)  
- State anxiety (State Anxiety Scale of the State-Trait Anxiety Inventory) | - Social support and performance of various caregiving tasks associated with lower anxiety  
- Time since parent’s cancer diagnosis, disease characteristics associated with higher anxiety  
- Involvement in other age-normative roles did not protect ADCs from anxiety  
- Greater sense of filial obligation significantly correlated with higher anxiety |
| 10                                                     | Rozario et al (2000) Cross-sectional | Use a within-race gender approach to examine the association of social resources and depressive symptomatology among two groups of African American wives and daughters | - 100 wife caregivers; 358 daughter caregivers  
- Care-recipient population: general aging | - Depressive symptoms (CES-D)  
- Social participation (single item)  
- Satisfaction with family functioning (Family Functioning Scale) | - Lower satisfaction in family a functioning is associated with increased levels of depressive symptoms  
- Availability of secondary informal help significantly associated with lower depressive symptoms for daughters |
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| 8                                                       | Son et al (2003) Cross-sectional | To investigate the association of care recipient impairments, caregivers' perceived health and receipt of social support on Korean caregiver burden and | - 117 ACCs (82% daughters/daughters-in-laws)  
- Care-recipient population: Alzheimer’s Disease | - Burden (Korean Burden Inventory)  
- Satisfaction (Caregiver Satisfaction Scale) | - Care recipient impairments caused by memory and behavioral problems were found to be related only to burden  
- Variable of memory and behavioral problems was a significant predictor of strain  
- Perceived social support predicted ACC satisfaction |
| 10                                                      | Starrels et al (1997) Cross-sectional | To investigate: a) whether the level of parental impairment has a direct positive association with ACC stress and b) whether cognitive deficits have a greater effect than physical deficits on ACC stress and c) the effect of caregiving tasks on ACC stress | - 1585 ACCs (70% daughters)  
- Care-recipient population: general aging | - Caregiver stress (multi-item scale) | - Parent’s cognitive and behavioral impairments more strongly related to stress than physical impairment  
- Amount of care provided positively associated with stress for daughters |
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| 10 | Stephens et al (1997) a Cross-sectional | To examine the relationship of role spillover with psychological well being of daughter caregivers | - 105 daughter caregivers  
- Care-recipient population: general aging | - Role stress (multi-item scale)  
- Positive affect (Positive and Negative Affect Scales)  
- Depression (CES-D) | - Negative spillover from employment role was the strongest mediator of depression  
- ‘Good mood’ was the most commonly reported positive spillover  
- Positive spillover from employment role had direct effect on positive affect |
<table>
<thead>
<tr>
<th>Method Quality Rating for quantitative studies [max. 12]</th>
<th>Author (Year of publication)</th>
<th>Objective</th>
<th>Sample [caregiver and care-recipient population]</th>
<th>Health and well being outcomes (measurement instrument)</th>
<th>Key findings</th>
</tr>
</thead>
</table>
| 10                                                       | Stephens et al (1997) b Cross-sectional | To determine the stress exacerbating and stress buffering relationship on well being of daughters holding multiple roles | - 296 daughter caregivers  
- Care-recipient population: general aging | - Depression (CES-D)  
- Life satisfaction (multi-item scale)  
- Dispositional optimism (Life Orientation Test) | - Stress in parent care, wife and employee roles had simultaneous main effects on caregivers’ depression  
- Daughters experiencing higher levels of stress due to parent care reported greater depression  
- Depression was most often predicted by role stress whereas life satisfaction was most often predicted by role rewards |
| 11                                                       | Stephens et al (2001) Cross-sectional | To identify factors that differentiate women with various patterns of conflicting roles | - 278 daughter caregivers  
- Care-recipient population: general aging | - Depression (CES-D)  
- Leisure activity restriction (multi-item scale) | - Provision of instrumental assistance associated with leisure activity restriction |
<table>
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<tr>
<th>Method Quality Rating for quantitative studies [max. 12]</th>
<th>Author (Year of publication)</th>
<th>Objective</th>
<th>Sample [caregiver and care-recipient population]</th>
<th>Health and well being outcomes (measurement instrument)</th>
<th>Key findings</th>
</tr>
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<tr>
<td>9</td>
<td>Varona et al (2006) Cross-sectional</td>
<td>To identify the predictors of caregiver burden and to assess the effect of social support on stressors and perception of burden among Filipino ACCs</td>
<td>- 193 ACCs (152 daughters) - Care-recipient population: general aging</td>
<td>- Perceived burden (Kosberg and Cairl CCI)</td>
<td>- ACCs caring for parent with behavioral problems had higher burden perception&lt;br&gt;- The receipt of social support was associated with lower burden&lt;br&gt;- Longer caregiving hours and higher income associated with higher burden perception&lt;br&gt;- Higher level of education associated with lower perception of burden</td>
</tr>
<tr>
<td>10</td>
<td>Walker et al (1996) Longitudinal</td>
<td>To explain individual variability in caregiving satisfaction by examining the wear-and-tear hypothesis longitudinally, focusing on the impact of duration of caregiving or caregiving satisfaction</td>
<td>- 130 daughter caregivers - Care-recipient population: general aging</td>
<td>- Caregiving satisfaction (multi-item semantic differential measure)</td>
<td>- More care given over time and caregiving satisfaction decreases over time</td>
</tr>
<tr>
<td>Method Quality Rating for quantitative studies [max. 12]</td>
<td>Author (Year of publication)</td>
<td>Objective</td>
<td>Sample [caregiver and care-recipient population]</td>
<td>Health and well being outcomes (measurement instrument)</td>
<td>Key findings</td>
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</table>
| n/a                                                    | Ward-Griffin (2007) Qualitative | To develop a better understanding of the caregiving and care-receiving experiences of adult daughters and their mothers with mild to moderate cognitive impairment | - 15 daughter caregivers  
- Care-recipient population: dementia | - In-depth interviews asked participants about their experiences in providing care, the mother-to-daughter relationship and factors influencing the process of care | - Daughters who described having custodial and combative relationships with their mothers tended to report more burden  
- Daughters who described strength-based complementary and cohesive relationships tended to report more gratification |
| 10                                                     | White et al (2000) Cross-sectional | To explore the differences in depression, stress and rewards experienced by white and African American daughters and daughter-in-laws | - 317 daughter caregivers (261 white; 56 African American)  
- Care-recipient population: general aging | - Depression (CES-D)  
- Stress (multi-item scale)  
- Rewards (multi-item scale) | - African American daughters reported lower stress and higher rewards than white daughters  
- No race differences in depression  
- Income was a significant predictor of depression |
<table>
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<tr>
<th>Method Quality Rating for quantitative studies [max. 12]</th>
<th>Author (Year of publication)</th>
<th>Objective</th>
<th>Sample [caregiver and care-recipient population]</th>
<th>Health and well being outcomes (measurement instrument)</th>
<th>Key findings</th>
</tr>
</thead>
<tbody>
<tr>
<td>n/a</td>
<td>Wong (2004) Qualitative</td>
<td>To: a) examine the problems that arise from caregiving for elderly with severe physical limitations and b) focus on the paradoxes and tensions in the gendered meanings attached to family eldercare in Hong Kong and understand how they induce caregiver stress</td>
<td>- 3 son caregivers, 6 daughter caregivers, 7 daughter-in-law caregivers - Care-recipient population: general aging</td>
<td>- In-depth interviews asked participants to share their experiences, perceptions and thoughts around providing intimate care with follow-up questions about how sex, the body and gender make providing this care difficult</td>
<td>- Sexual taboos put constraints on the ACCs as they tried to perform intimate care tasks, which they reported increased their stress and anxiety while caregiving - Among all the different types of stress encountered by participants, the feeling of embarrassment was uniformly and repeatedly mentioned (i.e. embarrassment about encountering the naked body)</td>
</tr>
<tr>
<td>7</td>
<td>Yajima et al (2007) Longitudinal</td>
<td>To investigate the effects of physical, psychological and social resources on the incidence of depression over time in family caregivers of disabled elderly</td>
<td>- 235 caregivers (71 wives, 85 daughters, 79 daughter-in-laws) - Care-recipient population: general aging</td>
<td>- Depression (Japanese version of GHQ-12)</td>
<td>- Larger emotional support network was associated with a decreased risk for depression in daughter-in-laws</td>
</tr>
<tr>
<td>Method Quality Rating for quantitative studies [max. 12]</td>
<td>Author (Year of publication)</td>
<td>Objective</td>
<td>Sample [caregiver and care-recipient population]</td>
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<tr>
<td>7</td>
<td>Yeager et al (2010)</td>
<td>To: a) better understand which dementia diagnoses and subtypes might best account for CG burden and b) explore the influence of moderating CG characteristics on degree of burden</td>
<td>- 784 caregivers (398 ACCs-gender distribution unspecified) - Care-recipient population: dementia</td>
<td>- Burden (Zarit Burden Inventory) - Depression (Beck Depression Inventory-II)</td>
<td>- Diagnosis type, physical functioning and caregiver gender all had main effects on depression - Presence of psychosis in addition to dementia significantly increased burden</td>
</tr>
<tr>
<td>10</td>
<td>Zhan et al (2005)</td>
<td>To understand the major stressors to psychological and emotional well being of rural and urban Chinese ACCs</td>
<td>- 110 ACCs (51% daughters; 30% sons, 17% daughter-in-laws, 2% son-in-laws) - Care-recipient population: general aging</td>
<td>- Depression (CES-D) - Subjective burden (multi-item scale)</td>
<td>- Length of caregiving and extent of parental disability associated with subjective burden - Provision of greater instrumental support associated with higher levels of subjective burden - Higher level of education associated with higher reports of depression</td>
</tr>
</tbody>
</table>
3.1. Systematic review sample population

Of the 50 studies, 4 (8%) employed a qualitative methodology (either using the grounded theory tradition or qualitative descriptive method). One study (2%) used mixed methods (i.e. used quantitative surveys as well as qualitative interviews) and the remaining 45 (90%) used quantitative methodology. The mixed method study largely reported quantitative design and findings and thus it was evaluated using the quantitative methodology assessment tool. Additionally, the mixed-method study was grouped with the quantitative studies for the remainder of this chapter. Of the 46 quantitative studies, 12 (26%) were longitudinal, 31 (67.4%) were cross-sectional and 3 (6.5%) were panel. A longitudinal study follows people over time and can look at changes at an individual level (38). A panel study also follows people over time; however, individual differences are not always examined whereas changes at a group level are (38).

Of the 50 studies included in the review, 30 (60%) investigated adult daughter caregivers (ADCs) alone. Twenty (40%) studies investigated both sons and daughters, with daughters comprising more than half the sample in 15 (75%) studies and the gender distribution being unspecified in 5 (25%) studies. The number of participants in the qualitative studies ranged from 15 to 54, with the median being 27.5. For the quantitative studies, the number of participants ranged from 66 to 1585, with the median being 175.
3.2. Quality Assessment of Included Studies

3.2.1. Quantitative Studies

Of the 46 quantitative studies, none of the studies scored less than 6 out of 12 on our measure of methodological quality (See: Table 1.3). The median score was 10, with 15 (32.6%) studies achieving this score. None of the studies received a perfect score. Inter-rater reliability was 78.2% with disagreement existing predominantly on the items ‘specifies care-recipient population and needs’ and ‘definition of carer/caregiver provided’. These differences were resolved through discussion.

Table 1.3 – Methodological quality scores of quantitative studies

<table>
<thead>
<tr>
<th>Methodological Elements</th>
<th>Number of studies that met criterion (n=46)</th>
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<tbody>
<tr>
<td><strong>Design Features</strong></td>
<td></td>
</tr>
<tr>
<td>1. Hypothesis/hypotheses made explicit</td>
<td>n= 34 (73.9%)</td>
</tr>
<tr>
<td>2. Type of study made clear</td>
<td>n= 46 (100%)</td>
</tr>
<tr>
<td>3. Inclusion/exclusion criteria made explicit</td>
<td>n= 38 (82.6%)</td>
</tr>
<tr>
<td>4. Definition of carer/caregiver provided</td>
<td>n= 39 (84.8%)</td>
</tr>
<tr>
<td>5. Specifies care recipient population (e.g. illness they suffer from) and needs (e.g. ADL or IADL)</td>
<td>n= 38 (82.6%)</td>
</tr>
<tr>
<td>6. Outcomes and other variables described (e.g. confounding, independent)</td>
<td>n= 46 (100%)</td>
</tr>
<tr>
<td>7. Sample size justified</td>
<td>n= 3 (6.5%)</td>
</tr>
<tr>
<td><strong>Study Conduct</strong></td>
<td></td>
</tr>
<tr>
<td>8. Response rate (completers) described</td>
<td>n= 33 (71.7%)</td>
</tr>
<tr>
<td>9. Participants representative of population (i.e. not convenience sampling)</td>
<td>n= 21 (45.7%)</td>
</tr>
<tr>
<td>10. Statistical analysis addressed study objectives</td>
<td>n= 46 (100%)</td>
</tr>
<tr>
<td><strong>Results</strong></td>
<td></td>
</tr>
<tr>
<td>11. Participant characteristics described</td>
<td>n= 43 (93.5%)</td>
</tr>
<tr>
<td>12. Numerical description of outcomes given (e.g. p-values, medians/means, standard deviation)</td>
<td>n= 46 (100%)</td>
</tr>
</tbody>
</table>
3.2.1.1. Design Features

The large majority of the studies (74%) explicitly stated their hypothesis. Studies that did not receive credit for this item often described their study objectives or aims without stating the hypotheses being tested. In all 46 (100%) of the studies, we were able to identify the study design either based on the authors’ statement of design or the recruitment/data collection strategies described (e.g. data collected at different waves indicated a longitudinal study). Credit was given to 38 (82.6%) studies for indicating the inclusion/exclusion criteria for the caregivers they included in their studies. For the most part, inclusion criteria pertained to the amount of assistance caregivers provided (e.g. number of times a week, hours of care) and the type of assistance provided (e.g. helping parent with activities of daily living (ADLs) or instrumental activities of daily living (IADLs)). Often, these criteria also comprised the definition of ‘caregiver’ and were used to specify the care recipient population and needs. Some studies also defined ‘caregiver’ as the participant’s self-identification as the primary person who assists the parent. The care-recipient population was also described to include information about the source of the ADL or IADL limitations (e.g. old age, illness). All of the 46 studies (100%) provided a detailed description of the outcomes they were investigating (e.g. burden, depression, stress) as well as the measurement tools they employed (e.g. CES-D for the depression). An area of weakness was the studies’ failure to report a sample size justification, with only 3 (6.5%) of the studies successfully doing so. For studies that reported national survey data, the sample size justification may have been assumed due to the large data set. Alternatively, since some of the studies presented secondary data, sample size justifications may have been presented in original publications. For other
studies, the use of convenience sampling may have rendered the justification of sample size uninformative and thus it was excluded by study authors.

3.2.1.2. Study Conduct

Of the 46 studies, 33 (71.7%) were given credit for effectively describing their response rate. This entailed describing the number of participants initially screened and those lost to: a) ineligibility and b) follow-up. Only 21 (45.7%) of the studies were given credit for including participants in their studies that were representative of the population. Those studies that received credit used probability sampling (e.g. data from a national survey). Those studies that did not receive credit (54.4%) used convenience sampling (e.g. recruiting via newspapers, advertisements and healthcare sites and relying on participant self-referral). All of the studies were given credit for employing a method of statistical analyses that addressed the study objectives. These studies received credit if they explained the statistical tests and analyses they performed and how each contributed to testing their hypothesis or meeting their study goals.

3.2.1.3. Results

Overall, the studies included in the present review excelled at reporting their findings. All but 3 (93.5%) of the studies received credit for providing a clear description of the study participants. This included a description of demographic information (e.g. age, income, education) as well as caregiving involvement (e.g. number of hours of care provided, types of assistance provided). Studies that did not receive credit for this item failed to provide this information. Finally, all of the studies effectively presented a
numerical description of the outcomes under investigation. Studies received credit for reporting the results of their statistical analyses with reference to p-values, median/mean scores as well as standard deviations.

3.2.2. Qualitative Studies

3.2.2.1. Study Design

Overall, a qualitative methodology was found to be appropriate for all of the studies included in the review (n=4). This is largely attributed to the fact that the aims of the qualitative studies centred on gaining further insight into the experiences of caregivers and interpreting their subjective experiences. For example, Jolicoeur et al (39) aimed to understand how acculturation is associated with Mexican-American caregivers’ sense of burden. This was a largely explorative area of study and thus a qualitative approach allowed the researchers to gain insight into the caregivers’ experiences using their own terms. Further, one-on-one in-depth interviews were considered conducive to the studies’ goals of exploring the individual experiences of the participating caregivers. The studies, however, failed to provide an explanation or justification for the participants they selected. That is, authors did not explain why the participants they chose were the most appropriate of those they could have studied.

3.2.2.2. Study Conduct

In qualitative studies, recruitment often occurs until ‘saturation’ is reached (i.e. data collection strategies provide no new and different data than what has already been collected) (40). The qualitative studies in the present review, however, did not describe this feature of the qualitative methodology and whether or not it was employed in their
study. The authors of the qualitative studies did not sufficiently report on ethical considerations such as the institutional ethics approval process their studies underwent or how potential participants were consented. Additionally, the authors did not reflect on their own personal biases that may have influenced the data collection and analysis (i.e. they did not sufficiently report on their reflexivity). All but one of the qualitative studies explained their analysis process in detail. For example, Wong et al (41) described the contribution of the constant comparative method to theme generation as well as the contribution of member-checking to theme validity.

3.2.2.3. Study Findings

The statement of findings was a strength of the qualitative studies. All of the studies explicitly presented their findings with discussion of how the findings addressed their study objectives. Additionally, the studies made good use of raw data (e.g. participant quotations) to support the interpretation of findings and presentation of themes. All of the studies sufficiently explained how their findings contributed to the body of existing literature by highlighting findings that were novel or that had been previously overlooked in the literature. For example, the qualitative approach that Wong et al (41) took allowed for a better understanding of how ACCs internalize sexual norms and taboos and how this internalization adds pressure and stress to ACCs as they provide intimate care to a parent. Furthermore, study authors used their findings to make recommendations for future areas of research that would help expand our understanding of particular phenomena. Wong et al (41) point out that the added pressure ACCs experience as a result of sexual taboos has not been the focus of existing research. In
turn, future research that investigates gender and eldercare (particularly intimate care) would benefit from further investigating the implications that this pressure has for ACCs.

3.3. Well being outcomes

The included studies operationalized ‘well being’ in a variety of ways. Conceptually, well being included psychological, emotional and physical health components as well as general life assessments. A commonly investigated psychological element of well being was depression which was measured by 19 (41.3%) studies using the CES-D. Caregiver burden was also widely investigated (17 studies) using a variety of different measurement instruments (e.g. Zarit Burden Interview, Japanese Burden Interview). The emotional component of well being included caregivers’ reports of positive and negative affect, distress and anxiety. Physical health was often globally investigated, with caregivers being asked to report on the state of their overall physical health (e.g. “how have you been physically since taking on the caregiving role?”). Again, these facets of well being were assessed using various multi-item scales with little consistency in the use of measurement scales (i.e. various studies employed different measure scales). Finally, well being was sometimes conceptualized as the caregivers’ general life outlook including assessment of overall life satisfaction and quality of life. Measures included the Family Satisfaction Scale and the Medical Outcomes Study (MOS) SF-36.

3.4. Care recipient-related influences

The most common care recipient-related influences examined across the studies
were type of impairment (n=11) and the nature of the care provided by ACCs (n=11). Parental impairment was largely characterized according to physical (e.g. mobility) and cognitive (e.g. memory) abilities. Factors pertaining to the nature of caregiving related to the duration, amount and type (e.g. emotional versus instrumental support) of care provided by ACCs.

Seven studies found that cognitive impairments resulted in greater depression and higher burden for ACCs than physical impairments (42-48). Six studies demonstrated that while cognitive impairments were not significantly related to well being, the problem behaviors the parent exhibited as a result of cognitive impairment were. Specifically, behavioural problems were related to greater perceived burden, greater depression and less satisfaction (46;47;49-52). A study by Kim et al (53) found that heightened care recipient distress was associated with lower quality of life for ACCs.

Of the 4 studies that investigated the influence of caregiving duration on well being, 2 found that with increased duration of caregiving, ACC depression increased and satisfaction decreased (54;55) whereas one found that a longer duration of caregiving was associated with lower levels of subjective burden (56). One study found a significant association between decreased ACC satisfaction over time and increased amount of care provided over the years (57). Of the 5 studies that investigated how the extent of caregiving (i.e. amount of care provided) influenced well being, 4 found that a greater amount of care provided (i.e. a greater number of care hours) was associated with greater burden, stress and health strain (44;45;47;58). In two studies of adult daughter caregivers to cancer survivors, anxiety and depression was lower in caregivers doing more for the care-recipient (59;60). Another four studies explored the type of care provided (i.e.
instrumental versus emotional). One study investigated the influence of providing emotional support on well being and found that the provision of this type of support was associated with higher ACC well being (61). The other three studies found that providing instrumental support to parents was associated with lower well being, leisure restriction and higher perceived burden (46;56;61).

3.5. Caregiver-related influences

The caregiver-related influences on health and well being that were investigated included demographic factors (n = 11), psychological factors (n=12) and role involvement (n=8).

3.5.1. Demographic Variables (n=11)

Eleven studies compared demographic variables like gender, education, income, rural vs. urban living, and marital status with well-being. Two of three studies found that daughters reported more persistent depression symptoms over time (54;55) as compared to sons. In one study, women reported greater personal and emotional costs related to caregiving (i.e. exhaustion, perceptions of being overwhelmed), but also reported greater rewards (i.e., life satisfaction) than caregiving sons (62). Finally, one study found that cultural considerations (i.e. filial obligation norms) and being married had differential effects for daughters and sons. Greater filial obligation and being married was related to less depression and more happiness for caregiving sons but not for caregiving daughters (63).

There was inconsistency in study findings related to the influence of education on ACCs’ well being. Some studies reported that ACCs who possessed a higher level of
education reported less burden and depression and greater self-esteem (47;51;64). Other studies revealed that ACCs with lower education reported lower depression, lower hostility, higher psychological wellness and greater happiness (56;63). The findings for income were more consistent. Most studies found that low income was associated with poorer health and well being among ACC’s. Specifically, ACCs with lower incomes reported more burden (47;56), more depressive symptoms (65), less mastery, and poorer physical health and self-esteem (63).

A small number of studies examined the role of culture on caregiver well being and, in general, findings were not consistent. Some studies found that having a Hispanic or African American background was correlated with less depression, role captivity and stress and increased self-acceptance and satisfaction with caregiving (65;66). One qualitative study, however, revealed that Hispanic caregivers who spoke the language and adhered to traditions reported more burden and worse physical health than Hispanic caregivers who adhered less to traditional cultural norms (39). A study of Korean ACCs revealed that, contrary to the expectations of the authors, the effect of cultural factors (e.g. filial obligation, familial norms) on ACC well being was not greater than the effect of non-cultural factors (e.g. parental impairment, caregiver gender) (42). However, Lee et al (67) found that higher filial obligation was related to lower reported burden amongst Korean ACCs. A qualitative study conducted by Wong et al (41) also found that cultural taboos relating to gender and sex roles made it difficult to intimately care for parents. This was associated with anxiety for Chinese ACCs in cross-gender dyads (e.g. sons caring for a mother or daughters caring for a father) (67).
Finally, only one study investigated the influence of rural versus urban residence on caregiver well being and found that caregivers who resided in urban areas reported experiencing more stress (68).

3.5.2. Psychological variables (n=12)

A variety of psychological variables were examined. In some cases, there were direct effects of the psychological variables on caregiver well being. In other studies, psychological variables appeared to moderate the impact of other variables (e.g., care recipient factors, demographic variables) on caregiver well-being (e.g. burden, stress, satisfaction). Finally, in some studies, psychological factors were operationalized as well being outcomes. Examples of psychological factors included optimism (n=4), self-esteem (n=5), guilt (n=1) and psychological distress (n=1). Greater optimism was associated with less depressive symptomatology (69), increased life satisfaction (69-71) and was found to moderate the association of stress on ACC well being (69;72). Self-esteem was associated with less depressive affect (64) and moderated the association between parent-child relationship quality and reported depressive symptoms (i.e. closer relationships enhanced self-esteem and higher self-esteem was associated with lower depression) (43). Other psychological factors that were infrequently studied included guilt and the meaning given to caregiving by ACC’s. Gonyea et al (73) found that when ACCs described feeling guilty about failing to live up to personal standards or social conventions related to caregiving they reported more burden. Noonan et al (74) revealed that finding meaning (i.e. positive value) in caregiving related to reports of lower depressive symptoms by ACCs and higher self-esteem.
Perceptions of mastery in different roles (i.e. perceived control) was shown to
decrease depressive symptoms over time (51;71) and was associated with greater life
satisfaction (42). One study revealed that this was particularly the case when ACCs
reported high mastery of family roles (i.e. parent care role and spouse role) (71). Another
study found that higher mastery was associated with ACCs experiencing less role
overload (74).

3.5.3. Multiple roles (n=8)

Some studies examined the relationship between holding multiple roles (e.g.
caregiver, spouse, employee, parent) and ACC health and well being. Most studies found
that holding multiple roles did not relate to increased role strain, depression (51;59;75),
or anxiety (60). In fact, one study found that, when ACCs felt that they adequately
performed each of their roles, including caregiving, they reported better well-being and
lower negative affect (76). Stephens et al (70) found that the role of employment in
caregiver well being depended on perceptions of one’s job. When individuals reported
that positive elements (e.g. greater confidence and better mood) from their employment
role spilled over into the caregiving role, they experienced greater positive affect.
However, other studies found that holding multiple roles was problematic for caregiving.
For example, in a study of 1060 ACC, being employed in addition to being a caregiver
was associated with reports of higher depression and lower psychological well being
(63). Negative spillover from work (i.e. limitations on time and energy) to caregiving
correlated with higher depression (70). Few studies have looked at parenting roles and
caregiver well being. One study found that although there was no association between
caregivers’ reports of life satisfaction and their simultaneous occupation of the mother and caregiver roles, being a mother intensified the negative effects associated with holding other roles (e.g. employee, spouse) (77).

3.6. Social influences

The social influences on ACC health and well being included parent-child relationships (n=14) and caregiver support (n=12).

3.6.1 Parent-child relationship (n=14)

The quality of the parent-child relationship and its influence on ACC health and well-being was examined in 14 studies. Several studies focused on the association between the pre-caregiving relationship and ACC well being (58;63;78;79) while other studies investigated the association between the post-caregiving state of the relationship and ACC well being (49;75;80-82). Only one quantitative study (43) and one qualitative study (78) explored both the pre- and post-caregiving relationship and the associated changes in the relationship.

In the qualitative study, Grand et al (78) suggests that while spousal relationships don’t begin with any ‘debt’ at the time the caregiving role is undertaken, the filial relationship is often characterized by the notion that children are indebted to their parents. However, the findings related to ‘debt’ or ‘filial obligation’ were inconsistent. Some studies found that ACCs who were not providing care out of a sense of duty or debt (i.e. filial obligation) tended to experience more stress, burden and less happiness (63;78). That is, lower filial obligation was associated with poorer well being. Other studies
observed high filial obligation (i.e. being indebted to parents) to be associated with higher stress, anxiety and depression for ACCs (59;60). In summary, inconsistency exists in the literature with regard to whether having a greater sense of filial obligation is associated with better or worse well being.

Some research has examined the quality of the ACC’s relationship with their parent. Higher quality relationships were those that consisted of more secure attachment, greater family satisfaction as well as cooperative and positive exchanges with parents (79-81;83;84). Lower quality relationships were those that were characterized by relationship strain and conflict and that consisted of ambivalent or avoidant attachment styles (79). Most of the studies found that relationships that were perceived to be high quality by caregivers were associated with lower distress, strain, burden and depression in ACCs and enhanced self-esteem and satisfaction (43;49;58;75;80-82). Yet, one study found that relationship quality did not relate to ACC well being when instrumental support needs were high (61). The authors speculate that any positive effects of high-quality relations were ‘offset’ by the high demands entailed in the caregiving situation (61). A qualitative study by Grand et al (78) found that ACCs who expressed anguish concerning their past relationship with their parent experienced more intense burden. Similarly, a qualitative study by Ward-Griffin et al (81) found that custodial and combative relationships (i.e. focused on deficits or conflict) were related to higher caregiver burden. However, cooperative and cohesive relationships (i.e. focused on strengths and cooperation) were related to higher perceived gratification from the caregiving role (81).
3.6.2. Caregiver support (n=12)

Caregiver support included emotional support (e.g. spousal understanding, advice) and instrumental support (e.g. physical assistance with tasks) received by the caregiver. All of the 11 quantitative studies that explored caregiver support found that the presence of support was associated with ACCs reporting better health and well being (44;47;52;58;60;62;74;85-88). Social support was associated with lower anxiety, burden and health strain as well as higher satisfaction (44;47;52;60). Emotional support was related to less overload, risk of depression as well as social and recreational health strain (44;74;87). Consistent with this, Grand et al’s (78) qualitative study suggested that when spouses were understanding or provided support, the caregiving role was better tolerated. However, caregivers who were pressured by their spouses to choose between their marriage and the caregiving role experienced more stress.

4. Discussion

When adult children become caregivers, their parents become dependent on them for support and assistance. This situation is often a reversal of the traditional parent-to-child interaction where the child is dependant on the nurturing and support of the parent. This unique circumstance may have important implications for the caregiving experience of adult children and their well being while performing the caregiving role. No systematic reviews to date, however, had summarized and evaluated the literature focused on factors that are associated with adult children caregivers’ (ACCs) well being. The goal of this systematic review was to fill this gap by exploring similarities and differences in the literature about what factors relate to ACC well being. Further, this
systematic review aimed to evaluate the methodological strengths and limitations (e.g. reporting of definitions, design gaps) of included studies and thus we developed a methodological assessment tool that aided in this appraisal. This tool also contributed to our understanding of the range of variables examined and helped to identify where there were gaps in information.

Fifty studies were reviewed, with a breadth in the conceptualization of ‘well being’. Well being was often conceptualized as the ACCs’ subjective reports of their own health (e.g. emotional and physical health). Emotional well being was captured by assessment of factors such as depression, satisfaction and burden while physical health was often captured by asking ACCs to report on “how they were doing physically since taking on the caregiving role”. A wide range of factors associated with ACC well being were identified and could be categorized into those that were care recipient-related, caregiver-related and socially-related. The two factors that received the most attention were the parent-to-child relationship and caregiver support. Additionally, the association between well being and psychological factors such as mastery and optimism received attention. Though there was a breadth of factors investigated, when each is looked at specifically, less depth is evident. For example, the studies that investigated the parent-to-child relationship focused largely on the quality of the relationship in either its pre- or post-caregiving state. As such, the actual or perceived changes in the relationship were not captured by these studies and, in turn, the association between changes in relationship quality and well being remains unclear.
**Methodological Considerations**

Some of methodological concerns expressed by past systematic reviews in the field of caregiving are also evident in the present review. Only 15 (32.6%) of the 46 studies employed a longitudinal or panel design. This limits our ability to understand how components of ACC well being changes over time. Moreover, it provides little insight into which factors are associated with ACC well being over the caregiving trajectory (e.g. which factors are more or less associated with well being over time). This is a particularly noteworthy gap when it comes to understanding some variables such as relationships and how they change between the ACC and parent as a result of caregiving. Longitudinal research that looks at role conflicts and role overload would also beneficially contribute to our understanding of how changes in roles potentially impact the caregiving experience and caregiver well being.

Another concern lies in the variability of measurement tools used to assess well being outcomes. Though the majority of studies employed the use of the CES-D to measure depression and many used the Zarit Burden Index to gauge caregiver burden, other outcomes such as stress and physical health were not measured using a standardized and validated measurement instrument. Since this can limit the generalizability of findings, the body of literature on ACCs may benefit from research that aims to develop and validate measurement instruments for these commonly investigated well being outcomes.

The absence of a rigorous definition of ‘caregiver’ may also limit the generalizability of findings. Due to the preponderance of ‘caregiver’ definitions that exist in the literature, failing to include a clear definition makes it difficult to
contextualize and compare findings across studies (89;90). This can reduce the clinical and policy relevance of the research (89). Though most studies (84.8%) in the review received credit for reporting a ‘caregiver’ definition, an important limitation to note is the fact that studies that did not provide a definition often also failed to provide the inclusion/exclusion criteria for the study. As Greenwood et al (18) point out; this confounding element makes it difficult to conclude that ACCs in these studies have similar experiences to other ACCs. Future studies should ensure that their definitions clearly describe what constitutes a ‘caregiver’. For example, they should explain if an individual is considered a ‘caregiver’ based on: a) the number of tasks they help the care-recipient with; b) the type of tasks they assist with; c) the number of hours of care they provide; d) the frequency with which they provide care; e) the duration of care provided or f) a combination of these.

Since only 4 (8%) of the 50 studies included in the review employed a qualitative methodology, this indicates a gap in the literature. Qualitative studies facilitate the ability to capture in-depth rich information about processes and complex relationships among variables. Greenwood et al’s (18) systematic review of qualitative studies pertaining to stroke caregivers found that qualitative studies illuminated aspects of the caregiving experience that were otherwise missed by quantitative studies (e.g. the interaction between roles, relationships and caregiver well being). This notion is supported by the fact that the qualitative studies in the present review also described novel findings that had been previously overlooked in the quantitative literature. For example, Grand et al (78) noted that their qualitative design provided insight into how failed negotiations between ACCs and their parents underlie the caregiver stress process
– an element of the stress process that had not been previously considered. A qualitative design may particularly contribute to our understanding of parent-to-child relationships and their association with well-being. Though longitudinal studies are one way of investigating how the parent-to-child relationship changes over the caregiving trajectory, a qualitative approach where participants can reflect on and discuss changes that have occurred in the relationship may also importantly contribute to our temporal understanding of the association between relationships and well-being. Based on a limitation identified by the current review, future qualitative researchers should endeavor to better explain their reflexive process (e.g. their method of recognizing and minimizing the effect of their personal biases on data collection and analysis). This should entail an account of the characteristics and experiences they possess that may influence the research process (e.g. occupation, gender) as well as how their relationship with participants may influence data collection (e.g. power relations) (36). It is worth noting that though the present study identified reflexivity as an area of weakness in the qualitative study, this may have less to do with study authors’ actual reflexivity and more to do with the word limitations imposed by peer-reviewed journals (i.e. it is a reporting issue rather than a methodological flaw).

*Consistencies in the adult child caregiver (ACC) literature*

The studies agreed that positive psychological variables such as mastery, optimism and self-esteem were associated with lower depression for ACCs. Additionally, the included studies consistently revealed that having some form of support (e.g. emotional or instrumental) was associated with better well-being for ACCs (e.g.
higher satisfaction, lower burden). This was especially the case when the source of support was a spouse. Nolan et al (91) have discussed how these factors contribute to caregiver coping, with support acting as an ‘external’ resource and psychological variables of mastery and optimism acting as ‘internal’ resources (92). The studies that explored psychological variables (e.g. mastery, optimism, self-esteem) were largely cross-sectional studies. In turn, the existing literature has yet to provide insight into how these psychological variables change over time and how their association with ACC well being may change as a result. Future studies would benefit from employing a longitudinal design to capture the temporal nature of these elements. With regard to support received, only one study (45) in the present review investigated parental support and how it is associated with ACC well being. Though the ACC becomes the predominant provider of support once the caregiving role is taken-on, the parent may still provide some degree of support to the ACC while receiving care. Reciprocity of support in parent-to-child relationships has been demonstrated to influence ACC well being positively (45;93-95). Thus, future studies that explore the extent to which ACCs still receive support from their parents while performing the caregiving role and how this support may influence well being would further contribute to our understanding of this unique aspect of ACCs’ caregiving experience.

All of the studies that investigated the parent-to-child relationship and its association with ACC well being found that high quality relationships (e.g. close, attachment) were associated with better well being (e.g. lower distress, strain and burden). This association was evident regardless of whether studies had focused their investigation on the quality of the pre- or post-caregiving relationship. Only two of the
included studies (43;78) investigated both the pre- and post-caregiving relationship, thereby allowing the authors to report findings pertaining to ACCs’ perceptions of change and changes that occur in the parent-to-child relationship over time. The life course perspective highlights the importance of understanding the trajectory of the parent-to-child relationship (e.g. the pre-caregiving relationship, the post-caregiving relationship and the changes in the relationship) (63). Future research should prioritize expanding our understanding of actual and perceived evolutions in the parent-to-child relationship and how such changes may be associated with ACC well being. As previously mentioned, both a longitudinal or qualitative approach can be taken to contribute to our understanding.

Although several studies in the current review reported that involvement in a greater number of roles (e.g. spouse, parent, employee) was not associated with ACC depression (51;59;75), some studies suggest that there may important limitations on time and energy that create role conflicts for ACCs (70). This finding in conjunction with past literature indicates that subjective aspects of holding multiple roles (e.g. quality of role performance, perceptions of effort expended, importance of role) may be as important to caregivers as those that are strictly objective and quantifiable (e.g. time or money spent) (96). As with other factors in the present review, the majority of studies that explored the association of multiple roles with well being were cross-sectional. For this reason, little is know about issues of role conflict and details about ACCs’ experiences of role problems over time. The life course perspective indicates that role salience (e.g. role importance) and role performance changes over time, with an individual prescribing to a particular roles (e.g. ‘caregiver’) more or less over the course of their life (63). Arguably
then, ACCs’ commitment to various roles may change over time, influencing how the various roles they occupy conflict or agree. Future research that explores what types of changes occur over time would enhance our understanding of how these changes may be associated with ACC well being.

*Inconsistencies in the ACC literature*

Although the literature was consistent that a positive relationship was important to caregiver well being, perceptions of filial obligation were less consistent. This suggests that relationship aspects around caregiving can be complex. Future research needs a more in-depth analysis of the ways that relationships may facilitate or undermine caregiving and caregiver well being. For example, feeling obligated or guilty may result in ACCs providing more assistance to parents, but in the long run, may not contribute positively to caregiver well being if caregivers believe they are helping for extrinsic reasons (i.e. they “have” to) as opposed to intrinsic motivation (i.e. they “want” to) (97;98).

5. Strengths and limitations of the current review

Since systematic reviews of observational studies often omit an assessment of methodology (30), a strength of our review lies in the inclusion of an assessment and the subsequent discussion of methodological quality. These findings can help research advance by suggesting ways to improve future studies. Additionally, we included both quantitative and qualitative research to obtain a comprehensive view of research in this field.
Our review had some limitations. The great majority of the included studies were conducted in a North American setting. Consequently, the applicability of the findings to a more global context may be limited. Since the focus of the current review was on health and well being outcomes for ACCs, other areas of importance that are impacted by caregiving (e.g., financial status) may not have been captured, thereby excluding important facets of the caregiving experience. Additionally, since we excluded interventional literature, the present review may not have captured intervention-related associations with ACC well being. The exclusion of these latter two study areas may limit the breadth of well being outcomes captured and, in turn, the generalizability of the present review.

6. Conclusion

The present review reveals that there are a variety of factors associated with ACC experiences and well being. Several important gaps remain in this body of literature. First, we do not yet understand how relationships evolve and change over time in caregiving. Secondly, our understanding of how various roles intersect to facilitate or undermine caregiver well being over time is limited. The existing studies in this area have predominantly employed a cross-sectional design with few longitudinal studies exploring changes over time. However, since some adult children assume the caregiving role suddenly (e.g. in the case of sudden-onset illnesses or when other options for care fail), it may be difficult to study these individuals ‘before’ they take on the caregiving role. For this reason, a qualitative approach may be particularly useful to probe
relationship issues and ACC perceptions of relationship change in order to guide the
development of future research.
CHAPTER TWO

The Importance of Adult Daughters caring for Parents who have Experienced a Stroke
1. Introduction

Previous research on adult children caring for parents has focused primarily on progressively deteriorating conditions like dementia, or caregiving for conditions like cancer, which may be of shorter duration. To date, little research has explored caregiving for adult children caregivers (ACCs) of the stroke population. A stroke condition is potentially distinctive from other conditions in that its onset is sudden, its trajectory often fluctuates (e.g. some periods of recovery and some periods of decline), and it can have both physical and cognitive implications. To date, we do not have a good understanding of how these distinctive elements of a stroke may relate to the experiences of ACCs. Moreover, adult sons and adult daughters may have different experiences and needs from one another while caring for a parent. However, since adult daughters take-on the caregiving role more often than sons, this research will focus on their experiences. In the following sections I discuss the nature of strokes in more detail and how this is associated with the caregiving experience. Specifically, I discuss adult daughter caregivers (ADCs) to stroke survivors and how the type and amount of care they provide makes them an important population to investigate.

2. Stroke as a leading cause of disability

Stroke is a leading cause of disability among older adults (99). Moreover, the risk of having a stroke doubles every 10 years for those 55 years and older (100). Consequently, a significant proportion of the Canadian population (those aged 65+) will be at an increased risk for stroke. Early identification and treatment of stroke has meant that approximately 85% of individuals in North America (101) and 80% of individuals in
Europe survive a stroke episode (102). However, among those who survive, approximately 50% will live with moderate to severe cognitive and physical impairments, limiting their ability to fully care for themselves in the community (103).

At present, 300,000 Canadians live in the community with stroke-related limitations (104). A 2007/2008 report of Ontario stroke survivors revealed that after their stay in acute care, 14% of stroke survivors were discharged home with services, 41% were discharged home with no services, 7% were discharged to continuing care, 7% were discharged to long-term care and 23% were discharged to inpatient rehabilitation (105). Of those who were admitted to inpatient rehabilitation, 9% were discharged to long-term care while 82% were discharged home. Overall, approximately 78% of stroke survivors end up living in the community at some point after the stroke occurrence. About half of these stroke survivors live with physical and/or cognitive limitations that make it difficult for them to perform activities of daily living (ADLs) (i.e. dressing or bathing) as well as instrumental activities of daily living (IADLs) (i.e. shopping or going to appointments) (103).

The majority of the assistance that stroke survivors receive while living in the community is provided by their families (106). In 2007, family caregivers accounted for $25 billion in annual savings for the Canadian healthcare system (7), with stroke caregivers accounting for at least $150 million per year (107). As the percentage of those 65 and older nearly doubles in the next 25 years, the economic value of what family caregivers do will also increase. As a result, supporting families such that they can sustain their caregiving role continues to be a research focus.
Caregivers with better physical and mental well being provide higher quality home care over a longer period of time than caregivers with poorer physical and emotional well-being (108). For example, Mayo et al (109) showed that stroke survivors experienced reduced lengths of stay in hospital with no detriment to their health when their caregivers were well-supported and had a greater sense of well being. Stephens et al (110) and Zarit & Whitlatch et al (111) found that increased psychological stress experienced by dementia caregivers resulted in earlier institutionalization of the patient. As a result, improving caregiver well being has been and continues to be an area of significant focus in research studies and caregiver support programs.

3. The unique experience of stroke caregivers

While the onset of an illness such as dementia or cancer is often gradual, a stroke is a sudden and unexpected occurrence. This sudden and disruptive nature of a stroke can have important consequences for caregivers. For example, caregivers of stroke survivors have little time to emotionally and physically prepare themselves for the caregiving role and its associated responsibilities. As a result, the difficulties that individuals experience in trying to gather the resources needed to aid in caregiving (112;113) may be particularly challenging for stroke caregivers who have the added stress of gathering these resources within a shorter time frame. The initial ‘crisis’ period following stroke onset and the subsequent stay of the stroke survivor in acute care is often met by caregivers with little thought of the future (i.e. the focus is on the immediate health and stabilization of the stroke survivor) (114). In turn, stroke caregivers may exhaust their resources (e.g. time off work, energy) earlier in the caregiving trajectory as they attend to their loved one.
during the acute phase. This may leave them with fewer resources later on in their caregiving career. As caregivers exhaust their availability early in the stroke trajectory, it may leave little opportunity for them to receive caregiving training from healthcare professionals later on. This may reduce the quality of care that the stroke survivor receives and can add additional strain to the lives of caregivers who are often already distressed by: a) the threat to their loved one’s health and b) the need to reduce their involvement in other roles (63;70).

Stroke is often characterized by both physical and cognitive limitations. For example, one study found that 35% of stroke survivors experienced cognitive deficits, with limitations in the domains of language, memory, orientation and attention being most common (115). Because of this, caregivers can experience differential impacts on their well being based on the type of impairment the care-recipient has. Some studies revealed that cognitive impairments and severe physical limitations impact caregivers more negatively than mild physical impairments (116-119), although other studies failed to find such a relationship (63;120;121).

4. Adult daughter caregivers (ADC)

The issue of gender is an important consideration in caregiving discussions and is particularly topical when discussing adult children. Research regarding the gendered nature of caregiving is prevalent and reveals that females assume the caregiving role more often than males (122). In fact, a 2007 Statistics Canada survey demonstrated that 57% of Canadian caregivers were women (1). Moreover, adult daughters provide twice as much assistance as sons with instrumental activities of daily living (IADLs) and three
times as much assistance with activities of daily living (ADLs) (123). In a study aimed at understanding adult children’s obligation towards their parents, Stein (121) found that adult daughters reported more “felt obligation” towards parents than adult sons and, as a result, were more likely to become primary caregivers to their aging parents. The gendered nature of caregiving also extends to the types of caregiving tasks that are assumed. Male caregivers reported being regularly involved in providing instrumental supports such as aiding in the completion of household tasks (121). In addition to instrumental support, female caregivers were more likely to provide emotional support, which included listening, sharing feelings (121), showing warmth and discussing problems (124-126). The provision of emotional support seems to be more psychologically tolling on caregivers than assisting with physical tasks (127). This generally translated into poorer well being and happiness for adult daughters as compared to adult sons (128). As Mui (128) suggests, differences in gender socialization may predispose daughters to consider the provision of emotional support a critical element of their responsibility as a caregiver, leading them to place greater importance on their relationship with their parent than sons (128). As a result, meeting the responsibility of providing quality emotional support may add additional strain to daughters as they attempt to uphold the relationship with their parent.

Adult daughter caregivers (ADCs) are more likely to report that caregiving detracts from their other roles and interferes with their lifestyle than sons (129). With the increase of ADCs in the workforce and the responsibility for child rearing remaining predominantly with females (129), ADCs may find issues of role strain and role conflict particularly prevalent as they attempt to manage their domestic roles as parents and
spouses in addition to providing care and being actively involved in the workforce, social, and leisure activities. These role conflicts and strains can place their emotional and physical well-being at heightened risk. This emphasizes the importance of considering and addressing the needs of daughters, who appear to be a particularly vulnerable subset of caregivers.

5. The daughter-to-parent relationship in the context of the Life Course

For both parents and children, the provision of care is situated in a long history between the caregiver and the care-recipient. The life course perspective acknowledges that: a) family members lead “linked lives”, resulting in interdependent development (63) and b) the roles that people assume are constructed over time (63). Within the life course perspective, social constructionism accounts for way the parent-to-child relationship and the ‘parent’ and ‘child’ roles develop or are ‘constructed’ over the span of the ADC and parent’s lives (130). Symbolic interactionism also underscores the fact that such ‘construction’ of the relationship and roles is produced by both the parent and child as a result of their interactions (131). The provision of care by children is unique in that the nature of their relationship with a parent was, at one time, a period of dependence on the parent who, for much of the child’s life, would have been viewed as an authority figure who provided nurturing and resources. Upon assuming the caregiving role, however, the daughter becomes the provider of support as the parent becomes dependent on her for assistance. This may result in a shift in the relationship and a reversal in roles, which highlights the importance of exploring both these facets in the context of the perceived parent-to-child relationship trajectory.
The life course perspective suggests that the pre-caregiving relationship may have important implications for how the post-caregiving relationship develops. For example, a study by Whitbeck et al (132) revealed that adult children who recall being rejected or poorly supported by their parents in childhood are less likely to stay in touch with and show concern for their parents in later life. Within the life course perspective, attachment theory explains that parent-to-child bonds form early in life and continue to develop as children grow older. Based on their experiences of attachment with their parents in childhood and adolescence, children develop ‘internal working models’ that act as templates that underlie their future attachments and relationships (83). Consequently, the attachment bonds a child forms towards their parent early in life are often sustained well into adulthood and can frame the parent-to-child relationship in later life (82).

As highlighted by the systematic review in the previous chapter, the studies investigating parent-to-child relationships have all found high quality relationships to be associated with better well being for children performing the caregiving role (43;49;58;75;80;81;133). These studies, however, focused on either the pre- or post-caregiving relationship quality with only one of the studies investigated daughters’ reports of relationship changes over time (43). With the life course perspective highlighting the importance of perceived trajectories, a valuable area for future investigation would be ADCs’ perceptions of changes in the parent-to-relationship and how these changes may be associated with their well being.

6. Focus of thesis

Some elements of the caregiving context that are unique to adult daughter
caregivers (ADCs) are: a) the life-long development of the parent-to-child relationship and b) the normative ‘parent’ and ‘child’ roles that develop across the life course. The pre-stroke relationship and role expectations between an adult daughter and her parent not only carry over into the caregiving situation but may also be perceived by the daughter to change or evolve as a result of caregiving. Since few studies to date have investigated ADCs’ perception of relationship change (134) and their reports of relationship changes over time (43), it would be valuable to explore these features of the caregiving context and how they may be associated with the well being of adult daughter caregivers (ADCs).

Since stroke has a variety of unique elements (e.g. sudden onset, fluctuating trajectory, physical and cognitive implications), it is reasonable to conclude that caregiving in the context of this illness may have distinct implications for the experiences and well being of ADCs. Interestingly, though, no studies to date have looked at the parent-to-child relationship, ADCs’ perception of relationship change and the association of the two with ADC well being in the context of stroke. Moreover, no studies to date have taken a qualitative approach to explore these issues.

Therefore, this thesis aimed to perform a qualitative study to answer three research questions: 1) What aspects of the pre- and post-stroke parent-to-child relationship are associated with the ADC’s well being? 2) What types of changes in the parent-to-child relationship, if any, do ADCs perceive? and 3) Are these changes associated with ADC well being and, if so, how?

Well being is a difficult construct to define since its components are broad and many. For the purpose of the present study, well being will be conceptualized as the
caregivers’ subjective assessments (both positive and negative) (135) of components that include (but are not limited to) their happiness, life satisfaction, morale (136), emotional distress, psychological state, feelings of gain, physical health and quality of life (137).
CHAPTER THREE

QUALITATIVE DESIGN, METHODOLOGY AND RESEARCH QUESTIONS
1. Outline

This chapter describes the qualitative descriptive approach employed in the study and a discussion of its appropriateness to address the study objectives as compared to other qualitative traditions. This is followed by a detailed description of the participant selection process and the recruitment strategies employed. The data collection process of in-depth interviewing is explained with details on the interview questions and interviewing strategies. Finally, the thematic content analysis process by which the study themes were generated is described.

2. Research Design:

The objective of the qualitative study was to provide a descriptively rich account of how the pre- and post-stroke ADC-to-parent relationship and any changes in the relationship were associated with ADC well being. A qualitative descriptive method was selected as opposed to other qualitative methods like grounded theory and phenomenology. Research using grounded theory aims to use the experiences of individuals to build a theory or conceptual model (138). There currently exist a number of relationship theories and theories about role involvement, balance, and conflict. Therefore, the development of a theory was not considered the main goal of this study. Phenomenology aims to describe the “lived experience” of an individual recognizing that reality is based on an individual’s perceptions and can change over time (138). Although there were a number of elements of phenomenology that were similar to the methods used in this research, phenomenology is often non-directive and aims to construct a gestalt of a prototypical experience (138). This was not the goal of this study, which emphasized describing different facets of ADCs experiences (40;139) in a concise and
descriptively rich manner that remains true to the data with less interpretation than is sometimes associated with other qualitative traditions (140). This method of qualitative inquiry produces an account of the data that is easily interpreted by policy makers and practitioners, thereby making the findings meaningful to these key stakeholders and potentially applicable to care situations (139).

3. Participants:

In qualitative studies, participants are recruited with the goal of capturing a breadth of experiences. Analysis often occurs concurrently with interviewing and recruitment ends when “theme saturation” is reached (i.e., no new ideas are uncovered in participant interviews) (40). “Theme saturation” lends itself to the qualitative tradition since the researcher allows the participants to discuss what is of importance to them within the context of the broad research question and objectives. Consequently, questions are open-ended and probes are used to gain a rich depth of understanding of the issues and themes relevant to the participants (40). The number of participants required to reach ‘theme saturation’ is variable. Some literature suggests that most researchers achieve theme saturation with approximately 20 participants (40) while other literature proposes that fewer participants are sufficient (80;116;141;142). For this study, I recruited until saturation was reached.

Participants were eligible for this study if they were: 1) Female; 2) Caring for a parent who has had a stroke; 3) English-speaking; 4) 18 years of age or older; 5) Centrally involved in providing and/or coordinating care for their parent (i.e. aiding with 1 or more Activity of Daily Living at least once a week); 6) First or second time stroke caregivers (where the first stroke was mild); 7) Providing care in the context of the
Canadian healthcare system; and 8) Providing care for a minimum of 1 month but no more than 4 years. Adult daughters needed to have at least one month of caregiving in order to have had some experience as a caregiver and to be largely past the initial crisis phase of their parent’s stroke. Initially, we limited caregiving to the first two years of the caregiving experience. However, this restricted the pool of potential participants and made recruitment difficult within the timeframe of the study. Consequently, we decided to expand the inclusion time frame to the first four years of caregiving. Relaxing the time frame to four years was not anticipated to affect ADCs ability to provide a rich, retrospective reflection on the pre-stroke relationship with their parent. At the same time, expanding the time frame would allow for the capture of relationship changes that occurred later in the caregiving trajectory.

As discussed previously, cognitive impairments (as compared to physical impairments) may be more detrimental to caregiver well being (118). This may mean that physical and cognitive impairments resulting from stroke may differentially affect the patient/caregiver relationship and caregiving situation. Consequently, it is important to understand how the type of impairment the parent has may influence the relationship with the ADC and in turn affect her well being.

‘Purposive sampling’ is a strategy used by researchers to ensure the inclusion of participants who possess a characteristic or experience that may contribute additional or differential data to the study (40). For the present study, purposive sampling was used to ensure that the sample population included ADCs who were caring for parents with a cognitive impairment as well as those caring for parents with a physical limitation. As a
result, the study aimed to recruit a minimum of 5 ADCs to parents with cognitive impairments.

4. Recruitment:

Study recruitment involved four strategies: 1) recruiting from three rehabilitation centres in the Greater Toronto Area; 2) recruiting from two community stroke support programs; 3) recruiting via advertisements placed in a free community newspaper; and 4) recruiting via an email request for participants sent out to the University of Toronto rehabilitation sector. The rehabilitation centres included: 1) Toronto Rehabilitation Institute (TRI); 2) St. John’s Rehabilitation Hospital; and 3) West Park Health Care Centre. The community stroke support programs included: 1) The Aphasia Institute and 2) The York Durham Aphasia Centre. Since ADCs to stroke survivors are a relatively small population, we recruited from multiple health care sites to expand the potential participant pool. Additionally, recruiting from rehabilitation sites across the Greater Toronto Area facilitated inclusion of ADCs who experienced different service delivery models. We also recruited via community newspaper advertisements (See: Appendix A) and email to the university’s rehabilitation faculty, staff, and students (sector) (See: Appendix B) to enhance the breadth of the study’s results and implications (i.e. making the study findings transferable to ADCs not included in the study) as well as adding to the pool of potential participants.

Prior to beginning recruitment, the project was submitted and approved by each institution’s research ethics board (REB) as well as the University of Toronto REB. Each institution identified a key contact person to assist with recruitment at their location. The
liaison was given study information (i.e. objectives, eligibility criteria) and proceeded to transfer the information to the institution’s out-patient stroke team or to the support program leaders. When the out-patient stroke team members or support group leaders identified a potential participant, they notified the liaison who then approached the potential participant with information about the study. The liaison then asked the individual if they would like to receive more information from the graduate student conducting the study. If the individual agreed, they were contacted by the graduate student and given greater detail about the study (i.e. objectives, participant commitment), screened for eligibility and invited to participate in the study. If the individual agreed, an interview was scheduled.

Prior to conducting the interviews, a consent process was initiated. This entailed providing information about the study procedures (i.e. interview format, recording of interview), the measures taken to ensure confidentiality (i.e. de-identification of data and secure data storage) and the study risks and benefits (i.e. emotional reactions and ability to share feelings with an attentive listener). The participants were given as much time as needed to think about their potential participation and to ask questions prior to consenting. When the interview was being conducted over the phone, participants gave verbal consent and were later mailed a consent form to read over, sign and return to the graduate student. They were also mailed a copy of the consent form to keep for their own records (See: Appendix C). If the interview was conducted in-person, the consent form was signed by the participant prior to the initiation of the interview and the participant was given a copy of the consent form for their own records.
The newspaper advertisement was placed in the Monday and Tuesday editions of a community newspaper for one week. This free newspaper is widely available at metro stations and various newsstands in the Greater Toronto Area (GTA). It reports local, national and international news and includes both advertisements and a classifieds section. The advertisement provided a brief description of the scope of the study, outlined the inclusion/exclusion criteria, and provided a contact telephone number (See: Appendix A). A list of prepared screening questions was used to establish eligibility (See: Appendix E). If the participant was eligible, they indicated their preference to be interviewed in-person or over the phone and an interview time was scheduled. Prior to the interview, I followed the same consenting process as outlined above.

The email to the University of Toronto rehabilitation sector was similar to the newspaper advertisement. Again, it provided some detail about the study’s scope, outlined the inclusion/exclusion criteria, and provided a contact number and email address (See: Appendix B). Potential participants were screened and consented as described above.

5. Data Collection:

Each ADC participated in one in-depth interview that was either conducted over the phone or in-person. There is controversy in the literature about the potential loss of data quality with telephone versus in-person interviewing. Novick (143) suggests that there is little evidence to indicate that telephone interviewing compromises data quality or that in-person interviewing is superior. Furthermore, Sturges (144) did not observe differences in the quality or quantity of data obtained using telephone and in-person
interviews in the context of their study that explored correctional officers and visitors’ roles during jail-visitation times.

Each interview was guided by a set of open-ended questions that asked the ADCs to describe: a) their parent’s stroke experience; b) their roles and responsibilities prior to taking on the caregiving role; c) their feelings about becoming a caregiver; d) their caregiving experience; e) the pre- and post-stroke relationship with their parent; f) their pre- and post-stroke relationships with other people; and g) their experience with the health care system (See: Appendix F). By asking the ADCs to describe their caregiving experience and the pre- and post-stroke relationship with their parent and others, I aimed to capture the various features of both the relationship and caregiving context that may have affected the well being of the ADCs.

Throughout the course of the interview I used the “probing” method (144) in order to encourage ADCs to discuss topics in greater detail – especially when the topics appeared to be of relevance to the research questions. For instance, when describing their relationship with their parent, I would ask ADCs to elaborate on what they meant by certain terms used to characterize the relationship (i.e. ‘close’ or ‘good’). If the ADCs’ discussion began to focus on the parent’s experiences and needs, the probing method was useful for redirecting the conversation back to the experiences, needs, and well being of adult daughter caregivers.

To capture demographic information about caregivers and their parent, a short questionnaire was administered at the end of the interview. It assessed the ADCs’ age, employment status, marital situation and income level (See: Appendix G). When the interview was conducted in-person, the participants were given the option of completing
the questionnaires after the interview or taking them home and mailing them to the graduate student once complete. For over-the-phone interviewees, the questionnaires were mailed to the participants and returned using a self-addressed and postage-paid return envelope.

To ensure the inclusion of ADCs caring for a parent who has cognitive limitations, caregivers were asked to indicate the types of deficits their parent had. If the caregiver indicated that the parent had speech difficulties or intellectual limitations (i.e. decreased ability to reason, poor judgment) they were considered to be caring for a parent with some degree of cognitive impairment. The caregivers also completed the Revised Brain Impairment Behaviour Inventory (BIBI) (40) to describe the severity of the stroke survivor’s cognitive symptoms. The BIBI consists of 18 items that ask the caregiver how many times in the past two weeks they observed the stroke survivor behaving in a particular way, where the behaviour categories were apathy, comprehension/memory problems, depression/emotional distress and irritability. Each item could be rated on a scale of 1 (‘never’) to 5 (‘all the time’), with 90 being the maximum score. Higher BIBI scores indicate more cognitive symptoms.

In order to collect information about the caregiving context, the Caregiver Assistance Scale (CAS) (145) was used to measure the extent of care that the ADCs were providing. This questionnaire consists of 17 items that ask caregivers to rate the amount of support 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’), with a maximum possible score of 102. Questions include: “How much assistance do you provide in: transportation, giving medications, bathing, etc…”
Interview data was de-identified in the transcription process and the resulting electronic data is stored on a password-protected computer. For example, all names of people and places were removed from transcripts. Hard copies of the data were stored in locked filing cabinets. The de-identified hard copy data was stored separately from the data that had the ADCs’ personal information (i.e. placed in different filing cabinets). All electronic and physical data will be destroyed after the 7-year retention period.

6. Data Analysis:

Thematic content analysis is initiated by doing an open-coding of the transcripts. This entailed becoming immersed in the audio and transcript versions of the interviews and making note of first impressions of the data (40). The literature suggests that in this phase of the analysis process, researchers should be looking for features such as key messages and recurring use of metaphors or terminology (40). Based on the first impressions of the data, I developed the ‘codebook’, which is a set of common codes that are used to systematically label and compare all instances of particular concepts or themes throughout the transcripts (40) (See: Appendix H). To facilitate the performance of this step in the analysis process, I used Nvivo (40;146;147), which is a qualitative software package that allows the researcher to enter their ‘codes’ into the program and subsequently use the program to label each of the transcripts.

The coding process is often considered the “deconstruction” portion of the analysis (148). This fragmentation allows the researcher to understand the various facets of the data in isolation prior to understanding them in relation to the rest of the data. This stage of analysis initiates the process of theme generation. To perform this stage of the
analysis, I used NVivo to aggregate the transcript data that fell under each code. I then compared and contrasted the coded data until I was able to categorize similar ideas. The final phases of thematic analysis rest in the reiteration of the comparison and contrast process (40). The themes were established after several reviews of the categorized data and when the categories consisted of distinct enough ideas to be labelled as separate themes.

Triangulation is a method used in qualitative research that enhances the credibility of findings. Various types of triangulation exist but for this study, multiple analyst triangulation was used. Multiple analyst triangulation entails several researchers developing and participating in the analysis process in order to minimize the potential bias derived from having only one researcher’s perspective (149). To employ this method, my supervisor reviewed and contributed to the development of the codebook prior to its use, reviewed audio and transcript data and contributed to theme development. Additionally, my Program Advisory Committee (consisting of two additional members) received a selection of interview transcripts to review. Upon developing their opinions and perceptions of the key messages in the data, they contributed this knowledge to the theme discussions. Based on these discussions, some of the initial themes were deemed non-distinct and therefore collapsed. The themes were then further compared, contrasted and reorganized. Finally, themes were enhanced by the addition of detail from the data to support proposed ideas.
CHAPTER FOUR

Manuscript:

“When daughters become caregivers to a parent who has suffered a stroke: A qualitative exploration of how the parent-child relationship is associated with caregiver well being”

Note: As this chapter is intended to be a stand-alone manuscript, there is some repetition from previous chapters in the introduction and methods sections
1. Introduction

In North America and Europe, we are presently experiencing a demographic shift towards an aging population. Currently, 15% of the Canadian population is 65 years and older (1). The United States and Europe are similar, with those aged 65 or more comprising 12.8% and 17.1% of the population, respectively (2;3). With the Baby Boomer generation reaching retirement age, it is estimated that this percentage will rise to nearly 20% in both Canada and the U.S. by 2030 (1;2) and to nearly 40% in Europe (3).

Stroke is a leading cause of disability among older adults (99). Moreover, the risk of having a stroke doubles every 10 years for those 55 years and older (100). Consequently, a significant proportion of the North American and European population (those aged 65+) will be at an increased risk for stroke. Early identification and treatment of strokes has meant that approximately 85% of individuals in North America (101) and 80% of individuals in Europe survive a stroke episode (102). However, among those who survive, approximately 50% will live with moderate to severe cognitive and/or physical impairments, limiting their ability to fully care for themselves in the community (103).

Community care services to assist stroke survivors upon return to their homes are limited (7;150) and, as a result, the majority of assistance that stroke survivors receive in the community is often provided by the family. In 2007, the unpaid labour provided by family caregivers saved the Canadian healthcare system over $25 billion (151), with stroke caregivers in Ontario accounting for $150 million per year (107).

Since stroke is a sudden occurrence, caregivers of this population often have little time to be adequately prepared for the caregiving role. In turn, they may be more
vulnerable to the physical and emotional health declines associated with ill-preparation for the role (112). The cognitive consequences of a stroke also contribute to the difficulties that caregivers may experience. Approximately 35% of stroke survivors experience cognitive deficits, with limitations in the domains of language, memory, orientation and attention being most common (115). Since managing cognitive rather than physical limitations is often more challenging for caregivers (118), stroke caregivers may be more vulnerable to experiencing decreased well being than some other caregivers. When stroke caregivers are well supported (e.g. have informational, emotional and instrumental resources) in the community, however, it can offset the difficulties they experience. This, in turn, leads to the provision of higher quality care and better functional recovery and community re-integration of the stroke survivor (109;152). Conversely, when family caregivers lack support and resources, they experience greater financial, physical and psychosocial costs (153) and this can ultimately compromise the quality of care they are able to provide.

Studies in the past have focused largely on spousal caregivers. The demographic shift towards an elderly population, however, suggests that more elderly Canadians will experience aging-related disabilities (5). Arguably, then, support from adult children will be an indispensable resource for the disabled elderly (154-158). A 2007 Statistics Canada Survey discovered that 62% of Canadian caregivers were caring for an elderly parent or parent-in-law. With the aging population at an increased risk for experiencing a stroke, an increasing proportion of adult children caregivers (ACCs) will be assisting parents with stroke-related impairments. Adult children are often at a point in their lives where they are employed, married and have children of their own. Upon assuming the
caregiving role, adult children must adjust their lives in order to accommodate this added responsibility (50;70;70;155-158). The tension that can occur between the ACCs’ various roles is associated with poorer physical health and lower satisfaction (159).

Caregiving remains a gendered domain, with daughters providing 70-80% of the care that elderly parents receive (160). Since adult daughter caregivers (ADCs) are more likely than sons to provide emotional support while caregiving (121;161), the time and mental investment that this type of support requires places ADCs’ psychological well being at heightened risk (127). ADCs who report lower quality relationships with their parents also experience heightened emotional strain in the caregiving role (128). Differences in gender socialization may predispose daughters to consider the provision of emotional support a critical element of their responsibility as a caregiver and that may lead daughters to place greater importance on the relationship with their parent than sons (128). As a result, meeting the responsibility of providing quality emotional support may add additional strain to daughters as they attempt to uphold the valued relationship with their parent (128).

1.1. ADCs and the life course

The provision of care by children is unique in that the nature of their relationship with a parent was, at one time, a period of dependence on the parent who, for much of the child’s life, would have been viewed as an authority figure who provided nurturing and resources. Upon assuming the caregiving role, however, the daughter becomes the provider of support as the parent becomes dependent on her for assistance. This may result in a shift in the relationship and a reversal in roles, which highlights the importance
of exploring both these facets in the context of the perceived parent-to-child relationship trajectory.

Many theories suggest that the type of relationship a child has with their parent can influence the child’s emotional health both positively and negatively (43;125;133;162). The relationship between the ADC and her parent can be described according to attachment style, feelings of conflict or feelings of ambivalence (163). In a study of ADCs and their mothers, Carpenter (83) revealed that daughters who had more secure bonds to their mothers experienced less caregiver burden than insecurely attached daughters. Moreover, securely attached daughters were better able to provide the emotional support that mothers required (83). Marks et al (63) showed that a history of poorer relations between adult children and their parents resulted in decreased caregiver well being. The existing studies in this area, however, have predominantly focused on either the pre- or post-caring relationship quality with few having investigated daughters’ reports of relationship changes over time (43). With the life course perspective highlighting the importance of perceived trajectories, a valuable area for future investigation would be ADCs’ perceptions of changes in the parent-to-child relationship and how these changes may be associated with their well being. As has been previously mentioned, stroke is unique in as far as its onset and consequences for caregivers are sudden. In turn, this illness population may be pertinent to investigate the issue of the pre- and post-illness relationship as ADCs have little time to anticipate and adjust to the stroke’s implications for the relationship with their parent.

Though longitudinal studies are one way of investigating how the parent-to-child relationship changes over the caregiving trajectory, a qualitative approach where
participants can reflect on and discuss changes that have occurred in the relationship may also importantly contribute to our temporal understanding of the association between relationships and well being. Therefore, employing a qualitative design is efficient in as far as it is less time consuming and costly and contributes to our understanding by probing for details about perceived changes over time.

Well being is a difficult construct to define since its components are broad and many. For the purpose of the present study, well being will be conceptualized as the caregivers’ subjective assessments (both positive and negative) of components that include (but are not limited to) their happiness, life satisfaction, morale (136), emotional distress, psychological state, feelings of gain, physical health and quality of life (137).

1.2. Objectives

The pre-stroke relationship between an adult child and their parent not only carries over into the caregiving situation but may also change or evolve as a result of caregiving. With daughters becoming caregivers more often than sons and placing more importance on the relationship with their parent, exploring the parent-to-child relationship and its association with the well being of adult daughter caregivers (ADCs) helps us understand the experiences of this particularly vulnerable subset of caregivers. Despite the unique features of a stroke (e.g. sudden onset, fluctuating trajectory, cognitive and physical consequences), no studies to date have looked at the parent-to-child relationship, its evolution and the association with ADC well being in the context of this illness.
Therefore, the objective of this thesis was to conduct a qualitative descriptive study to answer the questions: 1) What aspects of the pre- or post-stroke parent-to-child relationship are associated with the ADC’s well being? 2) What types of changes, if any, do ADCs perceive in the parent-to-child relationship? and 3) Are these perceived changes associated with ADC well being and, if so, how?

2. Methods

2.1. Research Design

This research employed a qualitative descriptive approach to address the research objectives and provide a concise and descriptively rich account of whether the pre- and post-stroke relationship potentially relates to ADC well being and, if so, how this process occurs. Qualitative description provides a clear and concise description of the data, which allows policy makers and practitioners to easily interpret and employ the study findings (138;164)s.

2.2. Participants

The study recruited until theme saturation (i.e. no new ideas uncovered) was reached. Based on previous qualitative studies, the estimated sample size was 15-20 ADCs. Participants were eligible for this study if they were: 1) Female; 2) Caring for a parent who has had a stroke; 3) English-speaking; 4) 18 years of age or older; 5) Centrally involved in providing and/or coordinating care for their parent (i.e. aiding with 1 or more Activity of Daily Living at least once a week); 6) First or second time stroke caregivers (where the first stroke was mild); 7) Providing care in the context of the
Canadian healthcare system; and 8) Providing care at home for a minimum of 1 month but no more than 4 years. ADCs needed to have at least one month of caregiving in order to have had some experience as a caregiver and be largely past the initial crisis phase of the stroke. To expand the pool of potential participants, ADCs who had up to four years of caregiving experience were included. Relaxing the time frame to four years was not anticipated to affect ADCs ability to provide a rich, retrospective reflection on the pre-stroke relationship with their parent and was anticipated to reveal changes in the relationship that occur later on in the post-stroke trajectory.

‘Purposive sampling’ is a strategy used by researchers to ensure the inclusion of participants who possess a characteristic or experience that may contribute additional or differential data to the study (143). For the present study, purposive sampling was used to ensure that the sample population included ADCs who were caring for parents with a cognitive impairment as well as those caring for parents with a physical limitation. As a result, the study aimed to recruit a minimum of 5 ADCs to parents with cognitive impairments.

4. Recruitment:

Study recruitment involved four strategies: 1) recruiting from three rehabilitation centres in the Greater Toronto Area; 2) recruiting from two community stroke support programs; 3) recruiting via advertisements placed in a free community newspaper; and 4) recruiting via an email request for participants sent out to the University of Toronto rehabilitation sector. The rehabilitation centres included: 1) Toronto Rehabilitation Institute (TRI); 2) St. John’s Rehabilitation Hospital; and 3) West Park Health Care
Centre. The community stroke support programs included: 1) The Aphasia Institute and 2) The York Durham Aphasia Centre. Since ADCs to stroke survivors are a relatively small population, we recruited from multiple health care sites to expand the potential participant pool. Additionally, recruiting from rehabilitation sites across the Greater Toronto Area facilitated inclusion of ADCs who experienced different service delivery models. We also recruited via community newspaper advertisements (See: Appendix A) and email to the university’s rehabilitation faculty, staff, and students (sector) (See: Appendix B) to enhance the breadth of the study’s results and implications (i.e. making the study findings transferable to ADCs not included in the study) as well as adding to the pool of potential participants.

Prior to beginning recruitment, the project was submitted and approved by each institution’s research ethics board (REB) as well as the University of Toronto REB. Each institution identified a key contact person to assist with recruitment at their location. The liaison was given study information (i.e. objectives, eligibility criteria) and proceeded to transfer the information to the institution’s out-patient stroke team or to the support program leaders. When the out-patient stroke team members or support group leaders identified a potential participant, they notified the liaison who then approached the potential participant with information about the study. The liaison then asked the individual if they would like to receive more information from the graduate student conducting the study. If the individual agreed, they were contacted by the graduate student and given greater detail about the study (i.e. objectives, participant commitment), screened for eligibility and invited to participate in the study. If the individual agreed, an interview was scheduled.
Prior to conducting the interviews, a consent process was initiated. This entailed providing information about the study procedures (i.e. interview format, recording of interview), the measures taken to ensure confidentiality (i.e. de-identification of data and secure data storage) and the study risks and benefits (i.e. emotional reactions and ability to share feelings with an attentive listener). The participants were given as much time as needed to think about their potential participation and to ask questions prior to consenting. When the interview was being conducted over the phone, participants gave verbal consent and were later mailed a consent form to read over, sign and return to the graduate student. They were also mailed a copy of the consent form to keep for their own records (See: Appendix C). If the interview was conducted in-person, the consent form was signed by the participant prior to the initiation of the interview and the participant was given a copy of the consent form for their own records.

The newspaper advertisement was placed in the Monday and Tuesday editions of a community newspaper for one week. This free newspaper is widely available at metro stations and various newsstands in the Greater Toronto Area (GTA). It reports local, national and international news and includes both advertisements and a classifieds section. The advertisement provided a brief description of the scope of the study, outlined the inclusion/exclusion criteria, and provided a contact telephone number (See: Appendix A). A list of prepared screening questions was used to establish eligibility (See: Appendix E). If the participant was eligible, they indicated their preference to be interviewed in-person or over the phone and an interview time was scheduled. Prior to the interview, I followed the same consenting process as outlined above.
The email to the University of Toronto rehabilitation sector was similar to the newspaper advertisement. Again, it provided some detail about the study’s scope, outlined the inclusion/exclusion criteria, and provided a contact number and email address (See: Appendix B). Potential participants were screened and consented as described above.

5. Data Collection:

Each ADC participated in one in-depth interview that was either conducted over the phone or in-person. There is controversy in the literature about the potential loss of data quality with telephone versus in-person interviewing. Novick (144) suggests that there is little evidence to indicate that telephone interviewing compromises data quality or that in-person interviewing is superior. Furthermore, Sturges (144) did not observe differences in the quality or quantity of data obtained using telephone and in-person interviews in the context of their study that explored correctional officers and visitors’ roles during jail-visitation times.

Each interview was guided by a set of open-ended questions that asked the ADCs to describe: a) their parent’s stroke experience; b) their roles and responsibilities prior to taking on the caregiving role; c) their feelings about becoming a caregiver; d) their caregiving experience; e) the pre- and post-stroke relationship with their parent; f) their pre- and post-stroke relationships with other people; and g) their experience with the health care system (See: Appendix F). By asking the ADCs to describe their caregiving experience and the pre- and post-stroke relationship with their parent and others, I aimed to capture the various features of both the relationship and caregiving context that may have affected the well being of the ADCs.
Throughout the course of the interview I used the “probing” method (40) in order to encourage ADCs to discuss topics in greater detail – especially when the topics appeared to be of relevance to the research questions. For instance, when describing their relationship with their parent, I would ask ADCs to elaborate on what they meant by certain terms used to characterize the relationship (i.e. ‘close’ or ‘good’). If the ADCs’ discussion began to focus on the parent’s experiences and needs, the probing method was useful for redirecting the conversation back to the experiences, needs, and well being of adult daughter caregivers.

To capture demographic information about caregivers and their parent, a short questionnaire was administered at the end of the interview. It assessed the ADCs’ age, employment status, marital situation and income level (See: Appendix G). When the interview was conducted in-person, the participants were given the option of completing the questionnaires after the interview or taking them home and mailing them to the graduate student once complete. For over-the-phone interviewees, the questionnaires were mailed to the participants and returned using a self-addressed and postage-paid return envelope.

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many times in the past two weeks they observed the stroke survivor behaving in a particular way, where the behaviour categories were apathy, comprehension/memory problems, depression/emotional distress and irritability. Each item could be rated on a scale of 1 (‘never’) to 5 (‘all the time’), with 90 being the maximum score. Higher BIBI scores indicate more cognitive symptoms.

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6. Data Analysis:

Thematic content analysis is initiated by doing an open-coding of the transcripts. This entailed becoming immersed in the audio and transcript versions of the interviews and making note of first impressions of the data (40). The literature suggests that in this
phase of the analysis process, researchers should be looking for features such as key messages and recurring use of metaphors or terminology (40). Based on the first impressions of the data, I developed the ‘codebook’, which is a set of common codes that are used to systematically label and compare all instances of particular concepts or themes throughout the transcripts (146) (See: Appendix H). To facilitate the performance of this step in the analysis process, I used NVivo (40;147;148), which is a qualitative software package that allows the researcher to enter their ‘codes’ into the program and subsequently use the program to label each of the transcripts.

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CHAPTER FOUR

Manuscript:

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Stroke is a leading cause of disability among older adults (100). Moreover, the risk of having a stroke doubles every 10 years for those 55 years and older (101). Consequently, a significant proportion of the North American and European population (those aged 65+) will be at an increased risk for stroke. Early identification and treatment of strokes has meant that approximately 85% of individuals in North America (102) and 80% of individuals in Europe survive a stroke episode (103). However, among those who survive, approximately 50% will live with moderate to severe cognitive and/or physical impairments, limiting their ability to fully care for themselves in the community (7).

Community care services to assist stroke survivors upon return to their homes are limited (150;151) and, as a result, the majority of assistance that stroke survivors receive in the community is often provided by the family. In 2007, the unpaid labour provided by family caregivers saved the Canadian healthcare system over $25 billion (107), with stroke caregivers in Ontario accounting for $150 million per year (112;113).

Since stroke is a sudden occurrence, caregivers of this population often have little time to be adequately prepared for the caregiving role. In turn, they may be more
vulnerable to the physical and emotional health declines associated with ill-preparation for the role (115). The cognitive consequences of a stroke also contribute to the difficulties that caregivers may experience. Approximately 35% of stroke survivors experience cognitive deficits, with limitations in the domains of language, memory, orientation and attention being most common (118). Since managing cognitive rather than physical limitations is often more challenging for caregivers (109), stroke caregivers may be more vulnerable to experiencing decreased well being than some other caregivers. When stroke caregivers are well supported (e.g. have informational, emotional and instrumental resources) in the community, however, it can offset the difficulties they experience. This, in turn, leads to the provision of higher quality care and better functional recovery and community re-integration of the stroke survivor (152;153). Conversely, when family caregivers lack support and resources, they experience greater financial, physical and psychosocial costs (5) and this can ultimately compromise the quality of care they are able to provide.

Studies in the past have focused largely on spousal caregivers. The demographic shift towards an elderly population, however, suggests that more elderly Canadians will experience aging-related disabilities (154). Arguably, then, support from adult children will be an indispensable resource for the disabled elderly (70;155-158). A 2007 Statistics Canada Survey discovered that 62% of Canadian caregivers were caring for an elderly parent or parent-in-law. With the aging population at an increased risk for experiencing a stroke, an increasing proportion of adult children caregivers (ACCs) will be assisting parents with stroke-related impairments. Adult children are often at a point in their lives where they are employed, married and have children of their own. Upon assuming the
caregiving role, adult children must adjust their lives in order to accommodate this added responsibility (50;70;155-159). The tension that can occur between the ACCs’ various roles is associated with poorer physical health and lower satisfaction (160).

Caregiving remains a gendered domain, with daughters providing 70-80% of the care that elderly parents receive (121). Since adult daughter caregivers (ADCs) are more likely than sons to provide emotional support while caregiving (127;161), the time and mental investment that this type of support requires places ADCs’ psychological well being at heightened risk (128). ADCs who report lower quality relationships with their parents also experience heightened emotional strain in the caregiving role (128). Differences in gender socialization may predispose daughters to consider the provision of emotional support a critical element of their responsibility as a caregiver and that may lead daughters to place greater importance on the relationship with their parent than sons (128). As a result, meeting the responsibility of providing quality emotional support may add additional strain to daughters as they attempt to uphold the valued relationship with their parent (43).

1.1. ADCs and the life course

The provision of care by children is unique in that the nature of their relationship with a parent was, at one time, a period of dependence on the parent who, for much of the child’s life, would have been viewed as an authority figure who provided nurturing and resources. Upon assuming the caregiving role, however, the daughter becomes the provider of support as the parent becomes dependent on her for assistance. This may result in a shift in the relationship and a reversal in roles, which highlights the importance
of exploring both these facets in the context of the perceived parent-to-child relationship trajectory.

Many theories suggest that the type of relationship a child has with their parent can influence the child’s emotional health both positively and negatively (125;133;162;163). The relationship between the ADC and her parent can be described according to attachment style, feelings of conflict or feelings of ambivalence (83). In a study of ADCs and their mothers, Carpenter (83) revealed that daughters who had more secure bonds to their mothers experienced less caregiver burden than insecurely attached daughters. Moreover, securely attached daughters were better able to provide the emotional support that mothers required (63). Marks et al (43) showed that a history of poorer relations between adult children and their parents resulted in decreased caregiver well being. The existing studies in this area, however, have predominantly focused on either the pre- or post-caregiving relationship quality with few having investigated daughters’ reports of relationship changes over time (140;164). With the life course perspective highlighting the importance of perceived trajectories, a valuable area for future investigation would be ADCs’ perceptions of changes in the parent-to-child relationship and how these changes may be associated with their well being. As has been previously mentioned, stroke is unique in as far as its onset and consequences for caregivers are sudden. In turn, this illness population may be pertinent to investigate the issue of the pre- and post-illness relationship as ADCs have little time to anticipate and adjust to the stroke’s implications for the relationship with their parent.

Though longitudinal studies are one way of investigating how the parent-to-child relationship changes over the caregiving trajectory, a qualitative approach where
participants can reflect on and discuss changes that have occurred in the relationship may also importantly contribute to our temporal understanding of the association between relationships and well being. Therefore, employing a qualitative design is efficient in as far as it is less time consuming and costly and contributes to our understanding by probing for details about perceived changes over time.

Well being is a difficult construct to define since its components are broad and many. For the purpose of the present study, well being will be conceptualized as the caregivers’ subjective assessments (both positive and negative) (136) of components that include (but are not limited to) their happiness, life satisfaction, morale (137), emotional distress, psychological state, feelings of gain, physical health and quality of life (138).

1.2. Objectives

The pre-stroke relationship between an adult child and their parent not only carries over into the caregiving situation but may also change or evolve as a result of caregiving. With daughters becoming caregivers more often than sons and placing more importance on the relationship with their parent, exploring the parent-to-child relationship and its association with the well being of adult daughter caregivers (ADCs) helps us understand the experiences of this particularly vulnerable subset of caregivers. Despite the unique features of a stroke (e.g. sudden onset, fluctuating trajectory, cognitive and physical consequences), no studies to date have looked at the parent-to-child relationship, its evolution and the association with ADC well being in the context of this illness.
Therefore, the objective of this thesis was to conduct a qualitative descriptive study to answer the questions: 1) What aspects of the pre- or post-stroke parent-to-child relationship are associated with the ADC’s well being? 2) What types of changes, if any, do ADCs perceive in the parent-to-child? and 3) Are these perceived changes associated with ADC well being and, if so, how?

2. Methods

2.1. Research Design

This research employed a qualitative descriptive approach to address the research objectives and provide a concise and descriptively rich account of whether the pre- and post-stroke relationship potentially relates to ADC well being and, if so, how this process occurs. Qualitative description provides a clear and concise description of the data, which allows policy makers and practitioners to easily interpret and employ the study findings (145;164)s.

2.2. Participants

The study recruited until theme saturation (i.e. no new ideas uncovered) was reached. Based on previous qualitative studies, the estimated sample size was 15-20 ADCs. Participants were eligible for this study if they were: 1) Female; 2) Caring for a parent who has had a stroke; 3) English-speaking; 4) 18 years of age or older; 5) Centrally involved in providing and/or coordinating care for their parent (i.e. aiding with 1 or more Activity of Daily Living at least once a week); 6) First or second time stroke caregivers (where the first stroke was mild); 7) Providing care in the context of the
Canadian healthcare system; and 8) Providing care at home for a minimum of 1 month but no more than 4 years. ADCs needed to have at least one month of caregiving in order to have had some experience as a caregiver and be largely past the initial crisis phase of the stroke. To expand the pool of potential participants, ADCs who had up to four years of caregiving experience were included. Relaxing the time frame to four years was not anticipated to affect ADCs ability to provide a rich, retrospective reflection on the pre-stroke relationship with their parent and was anticipated to reveal changes in the relationship that occur later on in the post-stroke trajectory.

‘Purposive sampling’ is a strategy used by researchers to ensure the inclusion of participants who possess a characteristic or experience that may contribute additional or differential data to the study (40). Purposive sampling was used to ensure that the sample population included ADCs who were caring for parents with a cognitive impairment (e.g., communication difficulties, impaired reasoning and judgment) as well as those caring for parents with a physical limitation. Since cognitive deficits are less common than physical deficits, the study aimed to recruit a minimum of 5 caregivers to stroke survivors displaying cognitive deficits.

2.3. Recruitment

Participants were recruited from: 1) three rehabilitation centres in the Greater Toronto Area; 2) two community stroke support programs; 3) an advertisement placed in a free community newspaper; and 4) an email request for participants sent out to the University of Toronto rehabilitation faculty, students, and staff. For strategies 1) and 2), an institutional liaison aided in identifying potential participants and putting them in
contact with the researcher. Strategies 3) and 4) were on a self-referral basis and required potential participants to call or email the researcher. All participants were screened for eligibility by the researcher (e.g. central caregiver, providing care for a minimum of 1 month and no more than four years). To ensure the inclusion of ADCs caring for a parent who had cognitive limitations, caregivers indicated the types of deficits their parent had. If the caregiver indicated that the parent had speech difficulties or intellectual limitations (i.e. decreased ability to reason, poor judgment) they were considered to be caring for a cognitively impaired parent.

Prior to beginning recruitment, the study was reviewed and approved by each institution’s research ethics board (REB) as well as the University of Toronto REB. All of the ADCs who were recruited for the study received both written and verbal information about the study and associated risks prior to providing informed consent. Each ADC was given a consent form to sign and return as well as a copy of the consent form to keep for her own records. Upon completion of the interview and questionnaires, ADCs received a $25 gift card and a list of caregiver resources across the Greater Toronto Area in appreciation for their participation in the study.

2.4. Data Collection

Each ADC participated in an in-depth interview that was either conducted over the telephone or in-person. Each interview was guided by a set of open-ended questions that asked the ADCs to describe: a) their parent’s stroke experience; b) their roles and responsibilities prior to taking on the caregiving role; c) their feelings about becoming a caregiver; d) their caregiving experience; e) the pre- and post-stroke relationship with
their parent; f) their pre- and post-stroke relationships with other people; and g) their experience with the health care system. Throughout the interview, ADCs responses to questions were probed in order to elaborate on the various topics in greater detail.

For descriptive purposes, a demographic questionnaire collected information about the ADCs’ age, employment status, marital situation and income level. In order to collect information about the caregiving context, the Caregiver Assistance Scale (CAS) (145) measured the extent of care that the ADCs provided. The measure consists of 17 items that ask caregivers to rate the amount of support 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’). Total scores range from 0 to 102, with higher scores indicating more assistance is provided.

The caregivers also completed the Revised Brain Impairment Behaviour Inventory (BIBI) (165) to describe the severity of the stroke survivor’s cognitive symptoms. The BIBI consists of 18 items that ask the caregiver how many times in the past two weeks they observed the stroke survivor behaving in a particular way, where the behaviour categories were apathy, comprehension/memory problems, depression/emotional distress and irritability. Each item was rated on a scale of 1 (‘never’) to 5 (‘all the time’). Total scores range from 18 to 90, with higher BIBI scores indicating more cognitive symptoms.

2.5. Data Analysis

Thematic content analysis entailed identifying themes that emerged from the interviews with the ADCs (40). This type of analysis is initiated by doing an open-
coding of the transcripts. This entailed immersion into the audio and transcript versions of the interviews and making notes of first impressions of the data (40;148). Based on these impressions, I developed an exhaustive coding scheme which was applied to all transcripts (40). NVivo qualitative data analysis software (146) was used to facilitate the coding process. I then compared and contrasted the coded data until I was able to categorize similar ideas. The final phases of thematic analysis rest in the reiteration of the comparison and contrast process (40;148). The themes were established after several reviews of the categorized data and when the categories consisted of distinct enough ideas to be labelled as separate themes.

Multiple analyst triangulation was used to enhance the credibility of the findings (149). This method entails several researchers developing and participating in the analysis process in order to minimize the potential bias derived from having only one researcher’s perspective (149). I took primary responsibility for developing the coding scheme and coding all transcripts. My supervisor reviewed and contributed to the development of the codebook prior to its use, reviewed audio and transcript data and contributed to theme development. Additionally, two program advisory committee members received a selection of interview transcripts to review allowing them to contribute to discussions about the themes. Based on these discussions, some of the initial themes were deemed non-distinct and therefore collapsed. The themes were then further compared, contrasted and reorganized. Finally, themes were enhanced by the addition of detail from the data to support proposed ideas.
3. Findings

In total, 41 ADCs were referred to the study via the various recruitment methods. Of the 41, 8 (19.5%) could not be reached to schedule an interview and 4 (9.8%) declined the invitation to participate upon learning the details of the study. Three ADCs (7.3%) were rendered ineligible by the fact that the time elapsed since their parent’s stroke exceeded four years. One ADC (2.4%) was ineligible because she did not provide care in the context of the Canadian healthcare system and another ADC (2.4%) was ineligible because she had previously provided care to her parent for a major stroke.

The remaining 23 ADCs were included in the study. Of these ADCs, 12 (52.2%) were recruited from rehabilitation sites across the GTA, 5 (21.7%) were recruited from the advertisement in the newspaper, 4 (17.4%) were recruited from a recruitment email sent to the University of Toronto rehabilitation sector and 2 ADCs (8.7%) either self-referred or were referred by somebody else.

All 23 ADCs participated in an interview and all but one completed the self-administered demographic questionnaire (see Table 4.1). An in-person interview was conducted with three of the ADCs while the remaining twenty completed telephone interviews. The interviews lasted a median of 46 minutes (40-62.5). The interview data did not differ greatly between participants recruited using different recruitment strategies. The most apparent difference was that daughters who were recruited from specific healthcare sites predominantly discussed their experience at that healthcare location. Participants who responded to the newspaper ad and recruitment email, however, varied in terms of where the stroke survivor received care and therefore their discussions of healthcare experiences were somewhat more diverse.
Table 4.1- Demographic characteristics of adult daughter caregivers (ADCs)*

<table>
<thead>
<tr>
<th>Characteristic</th>
<th>Participants (n=22)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, number/median (range) in years</td>
<td>47 (38-54)</td>
</tr>
<tr>
<td>Marital status</td>
<td></td>
</tr>
<tr>
<td>• Married</td>
<td>14 (63.6%)</td>
</tr>
<tr>
<td>• Single</td>
<td>6 (27.3%)</td>
</tr>
<tr>
<td>• Divorced/separated</td>
<td>2 (9.1%)</td>
</tr>
<tr>
<td>Education</td>
<td></td>
</tr>
<tr>
<td>• Completed post-graduate</td>
<td>2 (9.1%)</td>
</tr>
<tr>
<td>• Completed university</td>
<td>7 (31.8%)</td>
</tr>
<tr>
<td>• Complete college</td>
<td>4 (18.2%)</td>
</tr>
<tr>
<td>• Completed less than college degree</td>
<td>9 (40.9%)</td>
</tr>
<tr>
<td>Income (annual)</td>
<td></td>
</tr>
<tr>
<td>• Over $70K</td>
<td>7 (31.8%)</td>
</tr>
<tr>
<td>• $50K-69,999</td>
<td>5 (22.7%)</td>
</tr>
<tr>
<td>• $40K-49,999</td>
<td>2 (9.1%)</td>
</tr>
<tr>
<td>• $30K-39,999</td>
<td>1 (4.5%)</td>
</tr>
<tr>
<td>• No response</td>
<td>7 (31.8%)</td>
</tr>
<tr>
<td>Provided care to parent previously (Yes)</td>
<td>3 (13.6%)</td>
</tr>
<tr>
<td>Primary daily activity</td>
<td></td>
</tr>
<tr>
<td>• Working for pay</td>
<td>10 (45.5%)</td>
</tr>
<tr>
<td>• Retired</td>
<td>4 (18.2%)</td>
</tr>
<tr>
<td>• Caregiver</td>
<td>1 (4.5%)</td>
</tr>
<tr>
<td>• Homemaker</td>
<td>4 (18.2%)</td>
</tr>
<tr>
<td>• Other</td>
<td>3 (13.6%)</td>
</tr>
<tr>
<td>Employment status change related to stroke (could select more than one answer)</td>
<td></td>
</tr>
<tr>
<td>• Quit job</td>
<td>3 (13.6%)</td>
</tr>
<tr>
<td>• Reduced work hours</td>
<td>3 (13.6%)</td>
</tr>
<tr>
<td>• Took paid leave</td>
<td>2 (9.1%)</td>
</tr>
<tr>
<td>• Took unpaid leave</td>
<td>2 (9.1%)</td>
</tr>
<tr>
<td>• Other</td>
<td>3 (13.6%)</td>
</tr>
<tr>
<td>Live with SS (Yes)</td>
<td>11 (50%)</td>
</tr>
</tbody>
</table>

* Values are the number (percentage) unless otherwise indicated

The ADCs were interviewed a median of 11 (IQR 1-22.8) months after the stroke event. The ADCs had been providing care for a median of 6 months (Range: 05.-36 months). The median caregiver assistance scale (CAS) score was 55.5 (IQR 32.5 – 63.6) (See: Table 4.2). ADCs reported more assistance to parents in the domains of
instrumental activities of daily living (IADL) (e.g. transportation, communication with healthcare professionals, managing services) than with activities of daily living (ADLs) except for communication. The only domain of activities of daily living (ADL) that ADCs reported comparable assistance in was that of communication (See: Table 4.2).

The median Brain Impairment Behavior Inventory (BIBI) score was 48.5 (IQR 42 – 62.5) indicating that the stroke survivors had moderate cognitive impairments (See: Table 4.2). ADCs reported the highest scores in the BIBI subscales of depression/emotional distress and apathy (See: Table 4.2). The majority of the ADCs described their parent as suffering from both cognitive and physical limitations, however, three ADCs discussed their parent as having predominantly physical limitations and two ADCs commented that the parent largely suffered from cognitive limitations.

### Table 4.2- The stroke caregiving context

<table>
<thead>
<tr>
<th>Caregiving context</th>
<th>N= 22</th>
</tr>
</thead>
<tbody>
<tr>
<td>Median time elapsed since parent’s stroke (months)</td>
<td>11 (7-22.3)</td>
</tr>
<tr>
<td>Median duration of care (months)</td>
<td>6 (3.3-28.8)</td>
</tr>
<tr>
<td><strong>Extent of care provided (CAS)</strong></td>
<td>55.5 (32.5-63.6)</td>
</tr>
<tr>
<td>[Score range: 0- 102]</td>
<td></td>
</tr>
<tr>
<td>How much assistance do you provide in ... **</td>
<td></td>
</tr>
<tr>
<td>Transportation</td>
<td>5 Instrumental</td>
</tr>
<tr>
<td>Giving medications/assisting with treatment</td>
<td>3 Activities of</td>
</tr>
<tr>
<td>Banking and financial management</td>
<td>5.5 Daily Living</td>
</tr>
<tr>
<td>Transfers</td>
<td>1 (IADL)</td>
</tr>
<tr>
<td>Co-coordinating, arranging and managing services and resources</td>
<td>6</td>
</tr>
<tr>
<td>Household responsibilities</td>
<td>5</td>
</tr>
<tr>
<td>Communicating with health professionals</td>
<td>6</td>
</tr>
<tr>
<td>Feeding</td>
<td>1 Activities</td>
</tr>
<tr>
<td>Dressing</td>
<td>1 Of Daily Living</td>
</tr>
<tr>
<td>Grooming</td>
<td>1 (ADL)</td>
</tr>
</tbody>
</table>

117
<table>
<thead>
<tr>
<th>Activity</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Toileting</td>
<td>0.5</td>
</tr>
<tr>
<td>Bathing</td>
<td>0.5</td>
</tr>
<tr>
<td>Ambulation</td>
<td>2</td>
</tr>
<tr>
<td>Managing the emotional changes</td>
<td>4</td>
</tr>
<tr>
<td>Communication</td>
<td>5</td>
</tr>
<tr>
<td>Monitoring the health of the care recipient</td>
<td>4</td>
</tr>
<tr>
<td>Managing behavior problems of care recipient</td>
<td>4</td>
</tr>
</tbody>
</table>

**Extent of stroke survivor cognitive impairment (BIBI)** *

[Score range: 18-90]

<table>
<thead>
<tr>
<th>Item</th>
<th>Score</th>
</tr>
</thead>
<tbody>
<tr>
<td>Has no interest in anything</td>
<td>4</td>
</tr>
<tr>
<td>Does not want to do anything</td>
<td>4</td>
</tr>
<tr>
<td>Just sits and watches</td>
<td>3</td>
</tr>
<tr>
<td>Has difficulty becoming interested in things</td>
<td>4</td>
</tr>
<tr>
<td>Waits for someone to do things he/she could do</td>
<td>3</td>
</tr>
<tr>
<td>Has difficulty thinking clearly</td>
<td>3</td>
</tr>
<tr>
<td>Loses track of time</td>
<td>3</td>
</tr>
<tr>
<td>Shows poor judgment</td>
<td>2.5</td>
</tr>
<tr>
<td>Does not understand information</td>
<td>4</td>
</tr>
<tr>
<td>Repeats questions/stories</td>
<td>2.5</td>
</tr>
<tr>
<td>Gets depressed</td>
<td>3</td>
</tr>
<tr>
<td>Becomes fearful/afraid</td>
<td>3</td>
</tr>
<tr>
<td>Cries easily</td>
<td>2</td>
</tr>
</tbody>
</table>

* Median score (IQR)

** Median score

Individual item range for CAS: 0-5 (0= none; 5= a lot) [Higher scores indicate more provision of assistance]

Individual item range for BIBI: 1-5 (1= never; 5= all the time) [Higher scores indicate more cognitive and behavioral symptoms]

### 3.1. Themes

Four key themes were identified. The first theme was that the pre-stroke ADC-to-parent relationship is associated with the decision to take on the caregiving role. The next three themes related to ADCs providing care to their parent and the changes that
occur in the parent-to-child relationship, the ADCs’ relationships with other people and 
caregiver lifestyle, outlook and well being (e.g. physical and emotional). The themes 
were linked in as far as they helped to emphasize how parent-to-child relationships shape 
the caregiving experience and, conversely, how the caregiving experience shapes 
relationships with parents and others. In the following sections each theme is described 
in detail using sample quotations from the participants to illustrate key points.

(1) The pre-stroke ADC-to-parent relationship is associated with the decision to take on 
the caregiving role

The ADCs described that the pre-stroke relationship they had with their parent 
influenced their decision to take on the caregiving role. In discussing the pre-stroke 
relationship, ADCs made mention of the quality of the relationship (e.g. close or ‘bad’) 
and qualified their characterization by reference to the amount of contact/communication 
they had with their parent, how they got along with their parent and the support that they 
received from their parent. Daughters discussed both their adult relationship with their 
parent as well as elements of their relationship as they were growing up. Daughters also 
described that the quality of the pre-stroke relationship with their parent was tied to their 
sense of obligation and ‘owing’ the parent. This motivated them to take on the 
caregiving role. Finally, the ADCs explained that an inherent element of the relationship 
with their parent was the concern they had for them. This concern motivated the ADCs 
to seek the best possible care for their parent. In turn, when the daughters perceived other 
options for care to be less conducive to their parent’s recovery, the concern they had for 
their parent motivated them to take on the caregiving role themselves.
**Relationship quality, concern and the up-take of the caregiving role**

ADCs described that ‘good’ relationships with their parents consisted of regular contact. Those daughters who were in contact (i.e. regular phoning and/or visiting) with their parents explained that they enjoyed spending time and speaking with their parent regularly, allowing them to share experiences and maintain close ties. The daughters who described infrequent or minimal phone calls or visits explained that they avoided contact with their parent due to conflicting personalities or the inability to communicate and converse. A good relationship also entailed the ADC ‘getting along’ with her parent. Some ADCs described the parent as a ‘friend’ and someone with whom they shared similar interests and enjoyed spending time with.

When ADCs had a good pre-stroke relationship with their parent, the decision to take on the caregiving role was an easy one to make. ADCs explained that because they loved and respected their parent, they were happy to take on the caregiving role. Several ADCs mentioned that if their relationship with their parent had been turbulent (e.g. they didn’t get along or were not ‘close’) they might not have been as inclined to be a caregiver. In my sample this wasn’t the case, however, so the ADCs indicated that they didn’t have to “think twice” about taking on the caregiving role. Some ADCs in the study described poor pre-stroke relationships. Though they ended up taking on the caregiving role, these ADCs did not discuss wanting to ‘give back’ to their parent and did not mention the pre-stroke relationship as a motivator for taking on the caregiving role.
Relationship quality, obligation and the up-take of the caregiving role

The quality of the pre-stroke relationship between the ADCs and their parents contributed to the ADCs’ feelings of obligation and ‘owing’ their parents. These feelings were discussed by ADCs as contributing to their decision to take on the caregiving role. ADCs’ discussions indicated that they considered obligation and ‘owing’ to be two distinct sentiments. Obligation was discussed as the sense of responsibility ADCs had to their family in general and their parent specifically. ADCs explained that because they felt an obligation to their parent, they wanted to do all they could to help them recover. Therefore, the ADCs’ sense of obligation was not discussed as a factor that forced them to take on the caregiving role, but rather, as a motivator of their decision. ‘Owing’ the parent, however, was not discussed as a ‘responsibility’ the ADCs had to uphold, but rather, as stemming from a reciprocal exchange of support. ADCs who had good relationships with their parent described having received support from their parent throughout their lives. In turn, they felt that because their parent had provided for them throughout their lives, they ‘owed’ their parent for this and wanted to ‘give back’. While some ADCs discussed specific things that they owed their parents for (e.g. emotional support, financial aid), other ADCs felt that they owed their parents simply by virtue of them being their parent. This is highlighted by one ADC who discussed owing her parents for bringing her into the world:

CG 11: “Because they (your parents) brought you into this world, raised you....so that means you owe them everything too....it’s sort of like giving back”

Participants described that positive pre-stroke relationships entailed the receipt of a great deal of support from the parent (e.g. the parent ‘being there’ for them, providing aid when ADC needed it). These ADCs described that this further compelled them to ‘give back’.
One ADC explained that because her mother had always supported her, she wanted to do the same in her mother’s time of need:

*C.G. 18: “Well she’s my mother; we’re very, very close. So of course. She needs me. Why wouldn’t I be here? She was always there for me”*

One caregiver who described having had a poor pre-stroke relationship with her dad also mentioned her sense of familial obligation in taking on the caregiving but did not mention it as stemming from the pre-stroke relationship with her father:

*C.G. 8: “I guess I don’t know how other people are in this situation, how they end up becoming a caregiver, but for me it was just like, ‘This is the right thing to do, so I’m going to do it’...like familial obligation”*

**Concern for the parent, other options for care and the uptake of the caregiving role**

When other options for care existed but were not pursued, it was usually because the ADC believed that she was the better option for quality care for her parent. This belief existed when: a) the ADCs’ personalities, dispositions or experiences were perceived as better-suited to the caregiving role than other family members; b) care alternatives were not thought to be conducive to parental recovery (e.g. nursing homes) and c) ADCs felt they were better suited to provide care because they were female.

The daughters described that even when other family members (e.g. parent’s spouse, sibling) were available to become the primary caregiver, their personalities and experiences were not as well suited as those of the ADC. Several ADCs had employment experiences that they felt contributed to their knowledge and ability to provide care to their parent. For example, one ADC described how working with disabled children in her profession made her a ‘natural’ choice for the caregiving role:
CG 12: “I’m just a really caregiving kind of person. In my job I worked in the school system with children with special needs. So...that’s my nature. To naturally want to do that”

Other ADCs described that their personality traits and attitude (e.g. patience, resourcefulness) predisposed them to being more ‘natural’ caregivers than others. Many ADCs recognized that nursing home or long-term care options existed but that these were absolute ‘last resorts’. Some ADCs explained that their parent would not want to be ‘put in a home’ and, thus, they avoided this option so as to not upset them. For the most part, ADCs were worried about how their parent would recover both cognitively and physically in a nursing home. One ADC commented that the type and amount of care her mother would receive in a nursing home would be of lower quality than that which she would receive if cared for at home:

CG 14: “The nursing home was the very last place that we wanted her to go because we figured that she still had a lot of healing to do...and if she was in a nursing home she probably wouldn’t improve because there wouldn’t be the stimulation and it just would be a lot harder to look after properly”

Several ADCs commented that their role as a ‘daughter’ or ‘female’ predisposed them—more so than male relatives—to becoming the caregiver. ADCs explained that they were more apt to provide intimate care (e.g., bathing, toileting) and emotional support (i.e. listening, talking, encouraging) to the parent. This was most pronounced when the ADCs were providing care to a mother (i.e. female-specific needs are better met by the daughter). This is reflected in one ADC’s comment where she explains why her brothers would not have been adequate caregivers to her mother:

CG 2: “I’m the only daughter, it was all put on me of course....My brothers aren’t going to go out and buy her nightgowns, you know. Or underwear or any
personal items that she needs. They’re not going to do that. They’re not going to be cooking for her. Just you know, things that a daughter or a female [does]”

(2) Changes in the parent-to-child relationship occur as a result of providing care

The ADCs felt that their relationship with their parent had changed since they began caregiving. ADCs largely discussed that—compared to the state the relationship was in prior to the stroke—a number of declines had taken place. These declines included: a) difficulties in ‘getting along’ with their parent; b) the reversal of the ‘parent’ and ‘child’ roles and c) a sense of loss in their relationship with their parent (e.g. communication with and support from their parent).

‘Getting along’ is difficult

ADCs described the new difficulties they encountered in ‘getting along’ with their parent while performing the caregiving role. Most of the ADCs did not discuss any difficulty in ‘getting along’ with their parent prior to the stroke. However, the expectations and demands for care that their parents developed as well as the stroke-related personality changes their parent experienced generated tension in the relationship. ADCs expressed their frustration with the inability to meet their parent’s expectations and inability to manage and cope with their personality changes.

ADCs commented that their parent expected them to be more available and able to do more than they felt was reasonable. One ADC described how she and her father differed in opinion about the amount of care she provided:

*CG 1:* “There was time when it was hard...they expect a lot...then you felt like they want even more than I can do...they think I’m not there enough and I thought I was there more than enough”
When parental expectations could not be met, ADCs became frustrated and this made interacting with their parent more difficult. Several ADCs explained that when their parent’s expectations were too high, it seemed impossible to please them. This ultimately caused the ADCs to feel under-appreciated. This is captured by one ADC who explained how she felt when her mother reacted poorly to her efforts to prepare her an enjoyable meal:

*CG 2:* “She said the meat was old, the meat was dry, she didn’t want to eat it. So I thought, ‘Damned if I do and damned if I don’t’”

ADCs also discussed their parent’s post-stroke personality changes as contributing to their feelings of under-appreciation. In many cases, ADCs described their parents as becoming more ill-mannered (i.e. irritable, demanding). When these changes manifested in the form of a harsh disposition towards the ADC, it made it difficult for her to feel as though she was pleasing her parent. One ADC described how her mother’s demanding attitude caused her to feel like she wasn’t doing enough:

*CG 15:* “She doesn’t realize she’s doing this but she can be short and very demanding…you tend to feel like you’re being unappreciated or that you’re not doing a good enough job because she has this kind of irritated manner”

Apart from the ADCs feeling under-appreciated, the parent’s mood or personality changes were discussed as being generally difficult to manage and deal with. Several ADCs explained that conflict arose between them and their parent as a result of their parent’s personality changes. This was due to the fact that the personality changes caused the parent to be less agreeable and cooperative with the ADC. Daughters indicated their parent had become more stubborn and less willing to comply with their assistive efforts (e.g. stimulating and engaging them, preparing them for appointments).
One ADC explained her frustration with her father’s ill-compliance and argumentative attitude—especially since she had his best interest at heart:

\[ CG 4: \text{“I guess I was angry and upset that he couldn’t see that I was only doing it for his own good”} \]

In many cases, the ADCs described the personality changes of the parent as being stroke-related (e.g. personality changes due to cognitive deficits). In some cases, however, the ADCs described that their parent’s personality changes stemmed from their upset over being dependent on their child. This is reflected in one caregiver’s comment about how her father constantly tries to show he doesn’t need her:

\[ CG 4: \text{“He becomes cranky towards me more than anybody else...he seems to go out of his way to prove that he doesn’t need me to help him...I was angry...I was upset”} \]

For ADCs who had a close and loving pre-stroke relationship with their parent, ‘getting along’ with their parent was especially difficult. These ADCs had a hard time coping with the personality changes and felt that they had to learn to ‘get along’ with an entirely different person. In one extreme case, an ADC explained that her father’s post-stroke demeanor was comparable to the death of the pre-stroke father she was familiar with:

\[ CG 17: \text{“His personality changes...things he would never ever say, he would say...and he was just a different person...that was difficult because it seemed like your father died ...and this new person had arrived”} \]

**Role reversal is associated with relationship loss**

The parent-to-child role reversal was one of the most difficult changes the daughters encountered while caregiving. ADCs described the role reversal they experienced in terms of: a) the type of assistance they were providing to their parent and
b) the direction of support provision (i.e. ADCs were providing support to parent rather than receiving it from them).

ADCs felt that the ‘parent’ and ‘child’ roles had reversed due to the types of tasks they were assisting their parents with. Several ADCs discussed the need to aid their parent with meal preparation and feeding. In some cases, the parent’s reliance on the ADC for this assistance was so extensive that the parent would not be fed otherwise. Many ADCs described the intimate care (e.g., toileting and bathing) that they had to provide to their parent as being difficult not only for them, but also for the parent:

CG 15: “We’ve had to adapt to me wiping her, you know, in the toilet... which has been difficult for her but we’ve all adjusted”

The ADCs recognized that this role reversal changed the nature of their relationship. One ADC commented that the type of support she was providing to her father was outside of what she perceived to be her ‘normal’ role as a child:

CG 21: “So it’s just the relationship and how the roles kind of are reversed... that’s kind of weird. You don’t normally have to bathe your parents...disciplining him, feeding him...taking him to the doctor. It’s totally role reversal”

Many ADCs went as far as to characterize their experience of the role reversal by comparing parent care to child care. Much like a child relies on their parent for everything, ADCs felt that their parents now did the same. The ADCs also explained that the way they interacted with and treated their parent was similar to the interaction with and treatment of a young child (e.g. disciplining, encouraging). One ADC provided an example of this as she discussed supporting her mother through the recovery process (i.e. the regaining of physical and cognitive capacity):

CG 12: “It’s like taking a kindergarten child...you have to go along with them and make sure that they’re comfortable for a few times and then when we all feel safe then she can do that on her own”
In other cases, ADCs explained that, like a child, their parent could not be trusted to be left alone and, therefore, required regular supervision. One ADC explained that while parent care was like child care in many ways, it was different in as far as her parent would not ‘grow-up’ and improve the way a child normally would:

*CG 21:* “When you raise a child, you go through the different stages, so you know that they’re becoming more and more independent and there’s variety. This seems to be the same thing day in and day out and you just get tired of the same thing”

The ADCs explained that the difficulties they encountered with role reversal were not limited to the types of support they were providing. For most ADCs, the fact that they were now providing support to their parent rather than receiving it was in itself troubling. The daughters described that prior to the stroke, they received a variety of tangible (e.g. financial, aid with upbringing of ADCs’ children) and intangible supports (e.g. their parent just “being there” for them) from their parent. Upon becoming the caregiver, however, this changed as they became the support-providers and their parents became the recipients. The fact that they were no longer receiving the same degree of support from their parent led the ADCs to feel that they had lost a significant aspect of the relationship that was present prior to the stroke. ADCs described cognitive deficits (e.g. impaired judgment and reasoning, speech capabilities) as limiting the parent’s ability to engage with them and provide the same quality guidance and advice that they had prior to the stroke. One ADC described that because of her mother’s post-stroke cognitive state and health condition, their interactions had become trivial:

*CG 18:* “We try and keep things pleasant...that’s it...we just talk to keep things pleasant...to just interact. There’s not too much substance”
Several ADCs described being ‘friends’ with their mothers prior to the stroke. The daughters explained that they and their mother would talk to one another, share experiences and spend time together (e.g. vacationing together or going shopping) the way ‘girlfriends’ would. After the stroke, however, the daughters felt that cognitive and physical deficits (e.g. speech loss, reasoning impairment or mobility restriction) prevented their parents from engaging with them in the same way they would have prior to the stroke (e.g. less involvement in outings and conversations). In turn, this led the ADCs to feel that they had lost that important quality of friendship in the relationship with their mother. Even daughters who did not describe being ‘friends’ with their parent noted a disturbance in the relationship as a result of the parent’s stroke-related deficits. These ADCs predominantly found that speech impairments made it difficult to communicate with their parent (e.g. understanding parent’s speech, having parent understand what they were saying). One daughter described the time-consuming and frustrating nature of communicating with her mother who suffers from aphasia:

   CG2: “Dealing with aphasia...that’s the most difficult thing...because as frustrating as it is that she can’t get it out, I’m just as frustrated wanting to know”

As a result of communication difficulties, many ADCs felt that they could not discuss the same things with their parents as they had prior to the stroke. Consequently, the ADCs felt that they had lost the depth and quality of their communication with their parent.

**Relationship enhancements**

Despite the various negative consequences for the ADC-parent relationship, ADCs’ also discussed certain positive relationship changes that occurred as a result of the caregiving situation. ADCs who had described a poor pre-stroke relationship with their
parent (e.g., poor communication, not seeing the parent, parent not “being there” for ADC) more commonly discussed positive changes to their parent-child relationship as a result of providing care than ADCs who described good pre-stroke relationships. These ADCs’ indicated that the caregiving situation brought them closer together. For some ADCs, this was because they began to spend more time with their parent than they had prior to the stroke. In other cases, the parent’s dependence caused ADCs to become more affectionate towards them. One ADC explained that her father’s condition allowed him to be more sensitive towards her and therefore helped to improve their relationship:

CG 8: “I think it made him probably more sensitive...maybe more caring... so it kind of took our relationship to a different level because he was able to show more emotion”

Even some of the ADCs who described their pre-stroke relationship with their parent as having been positive noted that providing care brought them closer to their parent. The caregiving situation appeared to enhance the ADCs’ sensitivity towards their parents and vice versa. Many ADCs commented on the more open expression of emotion between them and their parent. One ADC described the expression of emotion as a direct result of increased empathy:

CG11: “You feel more sorry for somebody in the sense that there’s more outpouring of love and wanting to help because you see that person in a vulnerable state, right”

(3) Changes to an ADC’s relationships with others arises from providing care to a parent

ADCs indicated that the relationship with their parent was not the only relationship affected by their involvement in the caregiving role. Relationships with their partners, children, friends, siblings and other parent also changed. For the most part,
tensions were generated in these relationships. The aspects of caregiving associated with
the tension are described in detail below.

The daughters described the parent care role as conflicting with the other roles
they occupied (e.g. mother, spouse/partner, friend). Due to the amount of time that they
dedicated to the parent care role, many ADCs felt that the time they had available to
perform other roles was constrained. This often resulted in ADCs feeling role overload,
where they lacked the time needed to sufficiently meet all role demands. In other
instances, ADCs explained that even when they were physically present with others, they
were mentally absent as a result of being tired or thinking about their parent. The ADCs
were aware that their reduced involvement as a mother and a wife took a negative toll on
those relationships. Several ADCs felt that they often failed to support their children or
‘be there’ for them in the way they should. One ADC commented:

CG 20: “I felt like my son probably didn’t have a mother for the most part...you
know, I would have done more things with him that you do with your kids...He
would ask me if I could do things...I had to say, ‘no, I’ll be with nana’...so I’ve
had to say ‘no’ to my son a lot”

Some ADCs commented that the age of their children played a role in how the caregiving
experience influenced that relationship. One ADC commented that because her children
were older (i.e. middle-aged adults) they were more understanding of her caregiving
responsibilities, whereas ADCs who had younger children (i.e. school-age and teenagers)
did not share this experience. For these ADCs, having young children meant that they
needed to provide them with more support and attention. Moreover, because the children
were young, they were less understanding of the ADCs’ involvement in the caregiving
role. As one ADC explains, the combination of these factors resulted in tension between
her and her children:
CG 5: “There was maybe just a little bit of tension initially with my children because they’re small and don’t understand the seriousness of the situation and I guess they couldn’t understand why I always had to go to the hospital”

The ADCs also discussed the tension that arose in their relationships with their partners. Several ADCs explained that their husband/partner was upset that they were becoming a secondary priority to their partner’s caregiving duties. One ADC’s comment reflects this:

CG 8: “With my partner who is far away, that’s really hard because he feels like he’s second most important...because a lot of my time is spent at home with my parents and helping my dad. So that’s kind of suffered”

Some ADCs who were married or in relationships (e.g. had a boyfriend) explained that even though they were less involved in the relationship, their partners remained understanding and sympathetic of their situation. For most ADCs this facilitated their performance of the caregiving role since their partner was a source of support rather than conflict. Several ADCs, however, did not share this experience. These ADCs explained that their husbands would ‘complain’ about the amount of time and effort they put into caregiving. In some cases, partners began to resent both the ADC and her caregiving role. One ADC’s comment reflects how these sentiments sometimes led the partner to request that the ADC reduce her involvement in caregiving:

CG 13: “My husband, like all husbands, will complain. Like, ‘Why are you running around?’ ...this and that...like, ‘Leave them alone’”

When this occurred, ADCs felt torn between their two roles (i.e. caregiver and wife/partner). Several ADCs explained that when it was difficult to reconcile the two roles they felt the need to ‘choose’ between them. Situations such as these increased the stress that ADCs felt while caregiving and several ADCs commented that they wished their partner was more supportive and understanding. ADCs responded to and resolved
their issues with an unsupportive spouse in several ways. Some ADCs explained that their husbands’ lack of support was eye-opening and that they had separated from them or were considering divorce. Other ADCs explained that they talked to their husbands and tried to ‘calm them down’. One ADC valued her marriage and chose to respect her husband’s wishes by decreasing her involvement in caregiving even though she did not agree with that approach.

Most of the daughters discussed upholding their family roles (as opposed to social roles) when they experienced time constraints. Several ADCs discussed losing friendships as a result of this prioritization. Some ADCs explained that because the caregiving role ‘engulfed’ their lives, they had little mental and physical energy to expend on the upkeep of friendships. Moreover, ADCs commented that due to the limitations on their time, they could not meet with friends as often as they would like. One ADC commented on how the caregiving role took over her life:

CG17: “I was completely shut off from every one of my friends...you’re just so absorbed with what’s happening....it kind of overtakes your life, you can’t really think about anything else”

Though most of the daughters made little mention of the state of their relationship with their siblings prior to the stroke, one daughter commented that she and her brother were close prior to the stroke and that the relationship between them had continued to be strong. Another ADC explained that her siblings were never dependable prior to the stroke and, thus, she was not surprised (though upset) by their limited involvement in caregiving.

In a few cases, daughters described that tension evolved in their relationship with their other parent (i.e. spouse of stroke survivor) while they were performing the
caregiving role. ADCs commented that much like with their siblings, there was disagreement with their other parent on how the stroke survivor should be cared for. The tension and disagreement was particularly high for one ADC who did not have a good pre-stroke relationship with her other parent. Some ADCs explained that because they and the other parent did not wish to upset the stroke survivor; a lot of the tension that built up from the caregiving situation was released on one another. One ADC described how her father began to argue with her rather than with her mother (the stroke survivor):

\[CG\ 15:\ “My\ parents\ would\ bicker\ as\ people\ that\ have\ been\ together\ 50\ plus\ years\ will…and\ none\ of\ that\ bickering\ ever\ happens\ anymore.\ It’s\ always\ my\ dad\ treating\ my\ mother\ like\ gold\ whereas\ I\ end\ up\ getting\ the\ brunt\ of\ some\ the\ bickering\ now”\]

Despite these tensions in the relationship with their other parent, a few ADCs noted some improvements including being more open with one another (e.g. sharing feelings and thoughts) and having more communication (e.g. talking more often and more extensively) than they had pre-stroke. One ADC discussed this new increased openness and communication:

\[CG\ 6:\ “My\ mom\ and\ I\ have\ actually\ really\ opened\ up\ towards\ each\ other\ a\ lot\ more\ than\ before\ with\ our\ feelings…she\ wouldn’t\ tell\ me\ what\ she\ worried\ about\ before\ and\ now\ she’s\ more\ open\ with\ me”\]

(4) Changes to caregiver lifestyle, outlook and physical and emotional well being arise from caregiving

The ADCs described that while performing the caregiving role, they experienced changes in their lifestyle, well being and life outlook. As a result of taking on and performing the caregiving role, ADCs described having to balance this responsibility with other roles. In an effort to achieve this balance, the ADCs made a variety of
lifestyle adjustments (e.g. reduced involvement in employment and leisure ventures). The ADCs also discussed how the types of support they provided to their parent (e.g. instrumental and emotional) impacted either their physical or emotional health. Despite some of the negative effects the caregiving experience had on the ADCs’ lifestyles and well being, ADCs still felt that some aspects of caregiving were positive. This sentiment predominantly related to the ADCs’ perception that their life outlook was enhanced (e.g. they began to value life and people more greatly).

**Role balance and lifestyle changes**

The ADCs described that parent care had become their first priority and, in turn, their own lives and involvements had become secondary. ADCs commented that because parent care was a primary concern, they dedicated a great deal of time to the caregiving role. This commitment took away from the time that the ADCs had available to perform their other roles and responsibilities. ADCs spoke about how this made ‘balancing’ everything difficult since they had more to do than time allowed. One ADC commented on how balancing her roles and responsibilities was like ‘juggling’:

*CG 18: “It’s just a matter of juggling. It’s not a matter of I don’t have time for any of it...or all of it...it’s just a matter of juggling”*

To enhance their ability to balance multiple roles, the ADCs discussed making a variety of lifestyle adjustments. With regard to employment, many ADCs reduced their work hours or delayed return to work so they could manage the demands of caring for their parent. Some ADCs reported role loss, having given up work altogether. ADCs who left work to care for their parent and delayed their return to work explained that their parent’s needs and uncertain recovery prevented them from committing to employment
opportunities. Some ADCs who were not employed commented that they considered themselves fortunate and recognized that employment would have made caregiving much more difficult and may have created feelings of resentment in their caregiving role. However, as one ADC’s comment depicts, giving up employment was not always done willingly:

\[ CG 20: \text{“I’ve been angry. I resented having to quit the full time job where I was making good money and I loved the job...I didn’t want to have to do that”} \]

In addition to the changes that ADCs made to their employment status, many also adjusted their living arrangements so as to co-reside with their parent. This was the case for ADCs who were in relationships (e.g. married, had a boyfriend) and those that were single. Some ADCs explained that they moved in with their parent while others arranged for the parent to live with them. This was largely done by ADCs to ensure the parent’s ability to return to the community and to guarantee their safety while they resided there. Again, ADCs’ comments indicated that they did not favor this lifestyle adjustment. One ADC described that co-residing with her mother was not ideal, which made the situation unpleasant:

\[ CG20: \text{“She came and lived with me for 6 months, which was not easy because I’m in a small house”} \]

It was also common for ADCs to reduce their involvement in leisure activities. Many ADCs described reducing the amount of time they spent travelling for pleasure. For the most part, this was because they needed to remain vigilant or did not have any options for caregiving relief. ADCs also discussed reducing their involvement in exercise and sports activities due to having less time and energy to spare.
The ADCs’ need for respite support emerged as they discussed their efforts to maintain some aspects of their lifestyles. In many cases, ADCs explained that the caregiving role took over their lives and that they needed to get away from the caregiving situation and have time to themselves. For those ADCs who received caregiving relief from family and friends, the caregiving role did not feel onerous. However, when the ADCs did not have this type of support or when they reported giving up many social and leisure activities, they felt burdened. One ADC commented on her need for ‘a break’:

\[\text{CG 3: “Having more caregivers other than family members...because it would give us, the family members, an opportunity to get away from the parent...give us some time that we can go out and have time on our own... Give me a break!”}\]

**Impact of caregiving on physical and psychological health**

The ADCs experienced changes to their physical and emotional well being while performing the caregiving role. Several ADCs explained that caregiving was physically and emotionally exhausting. Some ADCs explained that they were tired as a result of all the ‘running around’ they had to do (e.g. running errands for parent, trying to fulfill multiple obligations, commuting to and from parent). Other ADCs commented that they were either getting less sleep or sleeping poorly and were tired as a result. Sleep disturbances were attributed to anxiety over the parent’s health or having less time to get a good rest. In addition to being tired, ADCs discussed the impact that caregiving had on their physical health. ADCs commented that they experienced body pain as a direct result of providing instrumental assistance to the parent (e.g. aiding with mobilization). Other ADCs explained that the physical and emotional strain of the caregiving role caused them to get sick more often and to lose weight as a result of poor eating habits or loss of appetite. One ADC commented on how stress affected her weight:
CG 17: “It was very stressful…it took a toll on my personal health… I never knew what was stress before this happened…especially in the acute phases… I lost a lot of weight, I wasn’t eating”

Although many of the ADCs did not explicitly link the relationship with their parent to their well being while performing the caregiving role, their discussions implied that an association between the two existed. Regardless of the quality of the relationship between the ADC and her parent prior to the stroke, almost all of the ADCs described being sad, shocked and worried in response to their parent having the stroke. One ADC commented on her emotional response to her mom’s stroke:

CG 13: “It’s really sad, you know…not because I’m doing this (caregiving), just because it (the stroke) happened…you know, you always ask, ‘Why me? Why my family’”

ADCs who described a positive pre-stroke relationship with their parent did not mention any anger or resentment in taking on the caregiving role. Daughters who described a bad pre-stroke relationship with their parent, however, expressed that they resented having to disengage with their employment and leisure initiatives to care for their parent. One daughter who had a poor relationship with her dad described her upset over the way caregiving interfered with her involvements:

CG 8: “I think I was a little angry. Just out of frustration…I’m 23, I have so much going on”

Many ADCs noted that providing emotional support to their parent was more difficult than performing assistive tasks. The provision of emotional support required a psychological/mental investment on the part of the ADCs. The ADCs considered this investment to be more straining than physical aid. In many cases, ADCs strongly empathized with their parents and therefore felt and lived through the same emotions
their parent was experiencing. One ADC described this as riding along the “emotional roller coaster” with her parent:

   CG 6: “When I say emotional it’s because my dad goes through these emotions and I would have to ride along with it and then have to control my own temper”

Related to this was the way that ADCs emotional well being improved as the parent recovered and gained back some of their functioning. One ADC described how her stress level decreased as her father’s health stabilized:

   CG 17: “I think it’s a direct correlation. So as he was improving with his health and things were stable and he’s kind of returning back to how he was....then it was less stressful for me...so it’s definitely helped me in the stress state that I was in before”

The emotionally draining nature of the caregiving experience was further highlighted by the ADCs’ desire for emotional support. For the most part, they reported wanting someone they could ‘talk to’ or someone who could ‘be there’ for them and empathize with their situation. In many cases, ADCs described wanting this type of support from a peer who understood what they were going through and could offer advice or guidance based on their own experiences. One ADC expressed why she believed a peer support group would be beneficial:

   CG 11: “Just the caregivers...different ways of supporting or finding out from each other or ideas...knowing that we’re kind of all doing this....in their situation how is it going...there could even be someone in your neighbourhood that’s going through the same situation and how can you kind of support each other”

**Enhancements in life outlook**

ADCs’ life outlook appeared to change as they became more aware of the fragility of life and, therefore, began to value life more greatly. Many ADCs commented that their caregiving experience had taught them to live life to the fullest and not to delay
doing the things they want to do. One ADC explained that she’s learned not to dwell on things or to live in fear:

CG 16: “My mom (the stroke survivor) keeps reminding me that you can’t live life always thinking the worst is going to happen. You have to move on and continue with your life....life’s too short to not go out and do things”

In addition to valuing life in general, ADCs also became aware of the fragility and importance of relationships. As a result, they discussed placing greater emphasis on relationships with people in their lives and valuing those people more. Several ADCs expressed that they valued their parent more after nearly losing them to the stroke. The ADCs also mentioned that they no longer took their parent for granted and that they wanted to make the best out of their ‘second chance’. Some ADCs also commented that the caregiving experience revealed who their ‘true friends’ were and, in turn, they learned which relationships were of value and which were not worth dwelling on.

4. Discussion

Though several studies in the existing body of literature have explored how either the pre- or post-caregiving parent-to-child relationship is associated with adult children caregivers’ (ACCs) well being, few of these studies have explored the trajectory of the parent-to-child relationship and its association with well being. For this reason, the present study aimed to explore the adult daughter caregivers’ (ADCs) relationship with their parent who has suffered a stroke, how the ADCs perceived the relationship to change and if these changes were associated with their well being. This study aimed to answer three research questions. The first research question aimed to understand how the pre- and post-stroke state of the ADC-to-parent relationship is associated with caregiver
well being. The present study revealed that positive pre-stroke relationships between the daughters and their parents led them to happily take on the caregiving role with little stress and resentment. When the post-stroke relationship consisted of conflict with the parent (e.g. getting along was difficult), the ADCs’ emotional well being was negatively impacted as they described being frustrated and upset. The second and third research questions related to understanding whether the ADCs perceived any changes in the relationship with their parent and, if so, whether these changes were associated with their well being. It became apparent that an important component of the ADCs’ well being was their emotional responses to the changes they perceived in the relationship with their parent. The daughters in the study felt that, overall, their relationships with their parents had declined, which generated feelings of sadness and loss. This was largely because stroke-related impairments (e.g. communication limitations) and role reversals (e.g. assisting parent with dressing, bathing or feeding) led the daughters to feel that they had lost the nurturing and support of their parent. These findings will be discussed and elaborated upon in the following paragraphs.

4.1. Taking on the caregiving role

Though ‘taking-on’ the caregiving role is a difficult period of decision-making for some caregivers, this is not always the case (91). With regard to understanding how the pre-stroke relationship affects caregiver well being, it became apparent from ADCs’ explanations that that they didn’t have to ‘think twice’ about becoming caregivers and did so happily due to the positive pre-stroke relationships (e.g. close) they had with their parent. In addition to the affection and closeness between daughters and their parents,
ADCs explained that their sense of obligation and ‘owing’ the parent contributed to taking on the caregiving role. Though ‘obligation’ has often been given a negative connotation in the literature (i.e. ACCs ‘have to’ provide care) (97), the ADCs in the present study described that they wanted to ‘give back’ to their parents and, therefore, were happy to fulfill their responsibility to care. Since the daughters in the study who expressed the most obligation were those who reported having better relationships with their parents, it may be interesting for future research to test the potential link between relationship quality and feelings of obligation. Such research would contribute to our understanding of whether feelings of filial obligation override poor pre-caregiving relationships with the parent or if they are a result of high quality relationships.

The present study predominantly included daughters who described positive pre-stroke relationships with their parents. It was apparent that positive pre-stroke relationships contributed to the willingness of these ADCs to take on the caregiving role. In turn, the transition into the caregiving role for these daughters may be importantly different from the transition experience of daughters who have had poor relationships with their parents prior to the stroke. Future research that helps us understand the experiences of daughters who have had a poor pre-stroke relationship with their parent would provide a more complete understanding of the transition into the parent care role. It will also be important for future studies to investigate the experiences of those daughters who do not transition into the parent care role (e.g. those who refuse or decline the role). Investigating this population would provide important insight into the decision-making process that is associated with the uptake of the caregiving role, the factors
associated with subsequently declining the role and its relationship to caregiver well
being.

4.2. Perceived changes in the parent-to-child relationship

An important consequence of suffering a stroke is the cognitive impairment that
often ensues (166). In discussing their perceptions of relationship change, it became
apparent that the parents’ cognitive impairments (e.g. impaired reasoning, impaired
speech) impacted the ADCs’ emotional well being as it fuelled their sense of relationship
loss. This was especially the case when the ADC had described a positive pre-stroke
relationship with her parent (e.g. receiving advice from the parent, having regular
conversations). Most studies that have investigated parent-to-child relationship quality
and adult children caregiver (ACC) well being have demonstrated that positive pre-illness
relationships are associated with better ACC well being (43;49;58;75;80-82). However,
the present study indicates that the association between changes in the parent-to-child
relationship and ADC well being may be of importance. Although a positive pre-stroke
relationship may enhance ADCs’ well being during the uptake of the caregiving role, it
may cause them distress later on in their caregiving career as they become increasingly
aware of how that relationship has declined. This finding underscores research that has
emphasized that caregiver needs may change over time (114;167). This study in
particular points to changes in emotional needs or well being over time. It suggests that
clinicians need to provide timely support to adult daughters as they may require different
resources at different times along the caregiving trajectory. For example, daughters may
require informational support from clinicians earlier on their caregiving role but may
need clinicians to facilitate networking with peers later on. Furthermore, findings suggest that ADCs may need more support or opportunities to link with other caregivers who also have experienced a loss in relationships. For this reason, future interventions should not only focus on providing daughters with instrumental support or someone to talk to, but rather, providing them with these types of support as they relate to the relationship loses they experience (e.g. someone to talk to about the loss of a valued relationship).

This finding also indicates that the degree to which the parent-to-child relationship changes has important implications for well being. The literature that exists on adult children caregivers has largely focused on either the pre-caregiving or post-caregiving state of the relationship with less attention being paid to the trajectory of the relationship. Further research is needed to broaden our understanding of the changes that occur in the parent-to-child relationship when daughters become caregivers. Longitudinal studies would contribute to enhancing our understanding by measuring changes in both the relationship and well being over time while taking into account the pre-stroke relationship. Moreover, it would be interesting for studies to investigate whether the well being of daughters performing the caregiving role is uniquely affected by these changes or if post-illness changes in the parent-to-child relationship affect non-caregiving daughters’ well being to the same extent.

**4.3. Participation and Activity Restriction**

As part of the International Classification of Functioning and Disability (ICF), participation is defined as the involvement in life situations—especially involvement in social roles (168;169). The stroke literature has consistently found that both stroke
survivors and their caregivers experience restrictions in activity and participation (170;171). In many cases, this translates into decreased well being for the caregivers and stroke survivors (e.g. heightened depression, lower satisfaction) (168). In the present study, the ADCs all reported making some sort of lifestyle change in order to accommodate the parent care role. In many cases, the taking on of a new role (caregiving) resulted in restricting involvement in employment or leisure activities (i.e., role loss in other areas). This highlights past literature that suggests that these changes are not uncommon (172), with caregivers often making at least one sort of adjustment to their lifestyle or other roles as a result of taking on the caregiving role. Since our findings and past literature indicate that caregivers are often only able to maintain the caregiving role by giving up other roles and responsibilities, the implications of this should be an area of focus for future research. Longitudinal studies would contribute to our understanding of which activities ADCs restrict their participation in temporarily and which persist over time. Moreover, longitudinal studies would allow us to understand whether caregivers perceive that their lifestyle adjustments result in a balance, a temporary limitation or loss, or whether they result in permanent changes. All of these changes may be associated with varying degrees of satisfaction or dissatisfaction that may relate to well being.

In the present study, ADCs’ commitment to the caregiving role caused tension in their relationships with other people. Importantly, the time-consuming nature of the parent-care role detracted from the amount and quality of time the ADCs spent with their partners and children. When the daughter’s partner and children were not understanding of her involvement in parent care, tension ensued and the daughter felt conflicted
between her roles. For this reason, clinicians should be aware of the demographic context in which an adult daughter is providing care. The present study indicates that daughters with young children and spouses may be more vulnerable to the role strains that ensue upon becoming a caregiver. This knowledge may facilitate clinician’s ability to identify at-risk caregivers and provide timely support. Given that the ADCs in the present study felt that their roles conflicted and that they had more responsibilities to fulfill than time allowed, future support programs would benefit from incorporating respite such that ADCs can have more time to be involved in their regular roles and activities. Additionally, family counseling may help ADCs, their partners and children work-through family conflicts that arise due to the ADCs’ involvement in parent care.

Though the daughters in our study predominantly discussed the hardships they experienced (e.g. relationship losses) and the detriments to their well being (e.g. poorer emotional and physical health) that resulted from the caregiving role, it is important to note that some benefits were apparent. Many daughters felt that they had gotten closer to their parent due to spending more time together, with this especially being the case for ADCs who had reported poor pre-stroke relationships with their parent. Daughters also felt that they became more open with their parent and that they gained a more positive life outlook (e.g. valued life and people more). As Kramer (173) has suggested, it is important for research not only to focus on the detriments or negative outcomes of caregiving but to investigate the positive aspects and gains as well. Our research highlights the fact that adult daughters do experience some gains from the caregiving experience and that future studies should explore aspects such as increased closeness and heightened emotional expressiveness in the parent-to-child relationship in greater detail.
5. Strengths and Limitations

To our knowledge no studies to date have qualitatively explored the pre- and post-stroke daughter-to-parent relationship and how changes in the relationship may be associated with ADC well being in the context of stroke caregiving. As such, a strength of this study lies in its contribution to the overall body of caregiving literature. The various recruitment strategies employed enhanced the breadth of experiences that were captured by the study and helped to reduce the biases associated with recruiting from only one location. An additional strength of the range of recruitment strategies used is that they have the potential to enhance the transferability of the findings. For this study, the goal was to capture ADCs who were in the early stages of their caregiving role such that they could better reflect on the pre-stroke relationship, how things had changed since they took on the role and how they were managing. Consequently, a strength of the study is the fact that the recruited ADCs were interviewed a median of 11 months after the stroke event and had been providing a median of 6 months of care. At the same time, future studies would benefit from using a longitudinal design where caregivers are interviewed about their relationship and well being over time.

The present study had a sample population that consisted of ADCs with predominantly positive pre-stroke relationships with their parents. As a result, this sample bias may have limited the study’s ability to capture important parent-to-child interactions that stem from poor relationships. Another limitation of the study may result from the retrospective element of recalling past relationships with the parent. Though we tried to reduce this limitation by including ADCs who had been caregiving for nor more than four years, the ADCs’ experience of the parent-to-child relationship while
caregiving may have altered their perception of the pre-stroke relationship. Future studies should aim to capture a more diverse sample of ADCs.

6. Conclusions

The present qualitative study reveals that adult daughter caregivers (ADCs) to stroke survivors draw upon the past relationship with their parent when deciding to become the caregiver. Positive pre-stroke relationships (e.g. close) motivated the ADCs’ obligation and concern towards the parent, leading them to willingly take on the caregiving role with little stress and resentment. The ADCs in the present study perceived the relationship with their parent to have changed. Daughters who had a positive pre-stroke relationship with their parent felt that the positive and valued aspects of that relationship had been lost to the parent’s stroke-related limitations (e.g. restriction in communication, restriction in parent’s ability to reciprocate support). The ADCs discussed how coping with these relationship losses was difficult and that they were often saddened by them. Since parent care was time consuming, ADCs often expressed that ‘juggling’ their multiple roles was tiring and required a variety of lifestyles adjustments to various roles in their lives (e.g. reduced work hours, reduced family time, less leisure activities). Additionally, they spoke of the tension in their relationships with others (e.g. spouse, children) that stemmed from spending a great deal of time in the parent care role. ADCs discussed their frustration when spouses and children were not understanding of the caregiving role but felt better able to cope with caregiving when they had the support of their loved ones. Finally, ADCs spoke about how caregiving impacted both their physical and emotional well being, with emotional consequences (e.g. increased stress, anxiety and sadness) being more difficult to cope with than physical consequences (e.g.
weight loss, body pains). Despite some of the negative impacts of caregiving, many daughters noted that the caregiving role was taken on willingly because of a positive pre-stroke relationship with their parent and that caregiving had brought them and their parent closer together.
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Appendices

Appendix A: Newspaper advertisement

RESEARCH STUDY
Are you a woman caring for a parent who has had a stroke?

We are looking for women 18+ who are providing care to a parent who has had a stroke 3-15 months ago to complete a short survey and participate in an interview.

For more information about this important study, please call Marina at the University of Toronto:

416-978-5694

UNIVERSITY OF TORONTO
Appendix B: Rehabilitation Sector Email

Are you a woman caring for a parent who has had a stroke? Do you know someone who is?

The study: An exploration of parent-child relationships and caregiver well-being that will help inform future research and caregiver support programs for adult daughters

Who can participate: Women who are 18 years or older who are helping their mom/dad with any of their usual activities or medications 3-15 months after their mom/dad had a stroke

Participants’ role: To be involved in one 60-90 minute interview about their relationship with their parent and their caregiving experience. The interview can be in-person or over the phone depending on the participant’s preference. Participants will also be asked to fill out a short survey about what they help their parent with and the limitations their parent experiences.

For more information: Contact Marina Bastawrous at 416-978-5694 or marina.bastawrous@utoronto.ca
Informed Consent Form for Participation in a Research Study

Family Caregiver Consent Form

STUDY TITLE: Adult daughters’ relationship with a parent who has suffered a stroke: A qualitative exploration of its association with caregiver well being

INVESTIGATOR:
Marina Bastawrous, MSc(c): 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 understand the experiences of adult daughters who are caring for a parent who had a stroke and to understand how their relationship with their parent influences their health and wellbeing.

Objectives
To understand what the experiences are of adult daughters caring for a parent who has had a stroke. We hope to learn about the history of the adult daughter to parent relationship and how the relationship has changed (or stayed the same) after the parent’s stroke. We also hope to learn how the relationship affects the well-being of adult daughters in the caregiver role and how this may influence daughters’ health service needs. We hope this information will help us enhance caregiver support programs by making sure that adult daughters’ needs are met. About 15 caregivers are expected to participate in the study.

Procedures
If you decide to participate in this study, you will participate in one 60-90 minute interview and fill out a short survey that asks about the things you help your parent with, the things your parent has difficulty doing and your parent’s behavior. Depending on
what you prefer, the interviews may take place in-person, at Toronto Rehabilitation
Institute, or over the telephone. The interview will take place at least 6 months after your
parent’s stroke and no later than 12 months post-stroke. You will have the right to not
answer any question, or simply ask to ‘pass’ any particular question you are not
comfortable answering. The discussion will be audio tape-recorded so that the researchers
can look back at your responses accurately, and use them to help us better understand
your experiences while caring for your parent.

Risks
Caregivers participating in our study will be asked to reflect on their experiences,
emotions, and readiness for caring for a stroke survivor post-stroke. To do so, caregivers
will be asked to participate in one interview that will last approximately 60-90 minutes.
This interview can be done over the phone or in-person at the participant’s location of
choice. The decision to hold the interview in-person or over the phone will be left up to
the participant. There is a possibility that the interview may be upsetting as you think of
your experience and the future. The 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 expressing 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 experiences may help other caregivers who take
on the parental caregiving role in the future.

Confidentiality

The 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 or the people at The Toronto
Rehabilitation, West Park, St. John’s or 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 hospital (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 about you that was collected before you
left the study will still be used. No new information will be collected without your
permission.

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 or travel costs 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 call Daniel Gyewu, research ethics manager at the University of Toronto at 416-946-5606. Mr. Gyewu is not involved with the research project in any way and calling the REB will not affect your participation in the study.

Consent
I have had the opportunity to discuss this study and my questions have been answered to my satisfaction. I consent to take part in the study. I may withdraw at any time without affecting the medical care of my loved one. I have received a signed copy of this consent form. I voluntarily consent to participate in this study.

________________________ ______________________   ________________
Participant’s Name (Please Print) Participant’s Signature       Date

I confirm that I have explained the nature and purpose of the study to the person named above. I have answered all questions.

____________________________     ______________________  _________________
Name of Person Obtaining Consent       Signature        Date
Appendix D: Screening questions

SCREENING QUESTIONS

1) When was stroke?

2) Who had the stroke?

3) Where were they hospitalized?

4) What type of stroke was it?

5) How long have they been home?

6) What things do you help with?

7) What kinds of problems does your parent have (mobility, speech, etc)?
Appendix E: Interview Guide

Interview Guide

To caregivers:

Throughout this interview I would like you to share your experiences of caring for your parent after their stroke. 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.

To interviewer:

6-12 months post-stroke may be a particularly emotional time for the caregivers. 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 caregiver is feeling too pressured, uncomfortable or upset to continue the interview.

1) If a caregiver explicitly says to stop the interview
2) If the caregiver 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 caregiver is crying to the point of being unable to speak

Upon stopping, ask the caregiver 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.

Interview questions:

1. Can you please start by describing your mom/dad’s stroke experience? Start with when the stroke happened and then discuss your parent’s movement through different healthcare settings and their final transition home
   Probes:
   • Where did the stroke occur?
   • How did they get to the hospital?
   • What was the care they received like?
   • What has your experience with the health care system been like? In acute care? In rehab? While at home?
   • What does your parent have difficulty doing?
   • How long was your parent in acute care and in-patient rehab?
   • How long has your parent been back home?

2. Can you describe what your life was like prior to your mom/dad’s stroke?
   Probes:
• What would a typical day be like for you?
• What did you consider to be most important about your life?
• How did you feel about your ability to meet your responsibilities and perform your different roles?

3. Can you describe how you felt when you became a caregiver for your parent?
   Probes:
   • How did you feel emotionally?
   • How did you feel about your ability to be a caregiver?
   • Were you afraid/excited/anxious/etc?
   • Did you feel prepared?
   • Did you seek help? If so, from who?
   • Why did you take on the caregiving role?

4. Can you describe what your relationship was like with your mom/dad prior to their stroke?
   Probes:
   • What was your childhood relationship like?
     o Can you provide an example?
   • How were your teen years?
   • What’s been your experience as you’ve gotten older and started working/gotten married/had a family?
     o When did you move out?
     o How was your level of contact/communication with your parent?

5. Can you describe what your relationship with your parent has been like since their stroke?
   Probes:
   • How did you feel after the stroke happened?
   • How do you and your parent get along now?
     o What is a typical day with your parent like now?
     o How do you feel about your ability to communicate?
     o How do you feel about your ability to negotiate?
   • How do you feel about the type of care you provide to your parent?

6. Thinking about your caregiving experience, do you feel your relationship with your mom/dad has been a factor?
   • If participant responds ‘yes’: How so? Can you provide some detail?
   • If ‘no’: Why do you think that is? Has it been a factor in any other ways?

7. How have you been since you took on the caregiving role?
   Probes:
   • How are you physically?
   • How have you been feeling?
   • How are your sleeping habits?
• How are your relationships with other people? (i.e. children, spouse, friends, etc…)

8. Can you describe your caregiving experience thus far?
   Probes
   • What have you been helping your parent with?
   • How do you feel about your caregiving abilities?
   • [Probe for difficulties faced and benefits experienced]
     o Can you elaborate on why this was a positive/negative experience?

9. How have the other aspects of your life been?
   Probes
   • What has working been like since you took on the caregiving role?
   • How has parenting been?
   • How is your social and marital life?

10. Do you get assistance from others?
    Probes
    • Who?
    • What are they helping with?
    • Who deals with mom/dad if they get upset?
    • Who helps around the house and with errands?
    • How often do people help?
    • Do you have someone to talk to when you need to?
    • Are there any family members you don’t receive help from? Why do you think that is?

11. What has your experience with the health care system been like since your parent had the stroke?
    Probes:
    • What has been helpful?
    • What difficulties have you faced?
    • What would you like to be improved?
    • What might you keep the same?
    • What could be introduced to better meet your needs?

12. Do you have anything else you’d like to discuss or elaborate on regarding caring for your mom/dad that we haven’t discussed?

Thank you for your time.
Appendix F: Demographic questionnaire, Caregiver Assistance Scale (CAS) and Brain Impairment and Behavior Inventory (BIBI)

Subject number:______________  Interview date:___day___mth____yr  Evaluator:_____________________

Socio-demographic and health-related information

1. What is your age, in years? ________________

2. In which Country were you born? ________________

3. What was the first language you learned as a child? ________________

4. When did your family member have their stroke? ____ day ____ month ____ year.

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

6. Do you have children? (1)Yes  (2) No
   If yes, how many?  (1) one   (2) two   (3) three   (4) four   (5) >five

7. Do you currently live with the stroke survivor?
   (1) Yes, full time   (2) Yes, part time   (0) No

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

9. Have you provided care in the past? (1) Yes  (2) No
   If yes, for whom:_________________ and for how long:__________________

10. What is your current primary daily activity? (Please choose one)
    (1) caregiver
    (2) homemaker
    (3) working for pay: type of work?________________________
        /hrs/wk?__________
    (4) unemployed
    (5) receiving disability
    (6) retired
    (7) volunteer
    (8) student
11. If you are working with paid remuneration or unpaid (regular volunteering), has your status changed since your caregiving role?  
   (1) Yes  
   (2) No  

If yes, how has your paid employment / volunteer activities changed? Please check all that apply:  
(1) quit working/volunteering: specify previous job ___________________  
(2) changed job: specify new job ___________________  
(3) took unpaid leave of absence for __________ weeks  
(4) took paid leave of absence for __________ weeks  
(5) decreased hours of work/volunteering by __________ hours/week  
(6) increased hours of work/volunteering by __________ hours/week  
(7) started working/volunteering outside the home: specify new job __________  
(8) opened home business: specify type __________________________  
(9) other (specify): ____________________________________________  

12. What is the highest level of education you have completed? (Please choose one)  
   (1) Less than primary (grade 8)  
   (2) Completed primary  
   (3) Less than secondary  
   (4) Completed secondary  
   (5) Some College courses  
   (6) Completed College  
   (7) Some university  
   (8) Completed university (bachelor degree)  
   (9) Post undergraduate program  

13. Which of the following categories best describe your family income?  
   (1) Less than $20,000  
   (2) $20,000 to $29,999  
   (3) $30,000 to $39,999  
   (4) $40,000 to $49,999  
   (5) $50,000 to $69,999  
   (6) Over $70,000  
   (7) Pass  

**HEALTH ISSUES- please check all that apply to you –**  
Please indicate whether you are presently treated for each of the identified conditions.  

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

CAS (caregiver assistance scale)

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 your family member had a stroke.

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

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

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

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

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

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

8. How much assistance do you provide in bathing?
   0  1  2  3  4  5  6
   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)?

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

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

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

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

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

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

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Brain Impairment Behaviour Inventory – Revised

When someone has heart failure, they may have some behavioural changes, for example losing their temper easily. How often over the past two weeks have you observed the care recipient to behave in each of the following ways? If you have not observed the behaviour, please circle (1) to indicate not at all. Please circle the corresponding number ranging from one (1) "never" to five (5) "all the time".

How often during the past two weeks did you observe the care receiver behaving in this way?

1. The care receiver loses his/her temper easily.
   
   1  never  2  3  4  5  all the time

2. The care receiver does not want to do anything.
   
   1  never  2  3  4  5  all the time

3. The care receiver waits for someone to do things that he/she can do for self.
   
   1  never  2  3  4  5  all the time

4. The care receiver is impatient.
   
   1  never  2  3  4  5  all the time

5. The care receiver acts as if he/she has no interest in anything.
   
   1  never  2  3  4  5  all the time

6. The care receiver just sits and watches.
   
   1  never  2  3  4  5  all the time

7. The care receiver cries easily without apparent reason.
   
   1  never  2  3  4  5  all the time

8. The care receiver has difficulty becoming interested in activities.
   
   1  never  2  3  4  5  all the time

9. The care receiver gets tired easily.
   
   1  never  2  3  4  5  all the time

10. The care receiver does not understand information.
    
    1  never  2  3  4  5  all the time

11. The care receiver has difficulty thinking clearly.
    
    1  never  2  3  4  5  all the time
12. The care receiver shows poor judgment.

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13. The care receiver becomes uncooperative.

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14. The care receiver becomes fearful and afraid.

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15. The care receiver repeats questions/stories.

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16. The care receiver worries unnecessarily.

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17. The care receiver gets depressed.

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18. The care receiver loses track of time.

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Reference List

Appendix G: Codebook

Codebook

Context (Comments about the stroke incident)

Pre-stroke (PRS) Caregiver description
- PRS CG description_lifestyle
  - PRS CG description_lifestyle_work (Comments about the caregiver’s pre-stroke work life)
  - PRS CG description_lifestyle_family (Comments about the caregiver’s pre-stroke family life)
  - PRS CG description_lifestyle_social (Comments about the caregiver’s pre-stroke social life)
  - PRS CG description_lifestyle_living (Comments about the caregiver’s pre-stroke living arrangements)
  - PRS CG description_lifestyle_priorities (Comments about the caregiver’s pre-stroke priorities and prioritization)

- PRS CG description_health
  - PRS CG description_health_Emotional (Comments about the caregiver’s pre-stroke emotional health)
  - PRS CG description_health_Physical/somatic (Comments about the caregiver’s pre-stroke physical/somatic health)

Pre-stroke (PRS) Parental description
- PRS Parental description_Personality (Comments about the personality of the Parent prior to having had the stroke)
- PRS Parental description_Health (Comments about the health of the Parent prior to having had the stroke)
- PRS Parental description_Needs (Comments about the care needs of the parent prior to having had the stroke)

Post-stroke (POS) Parental description
- POS Parent description_Personality (Comments about the personality of the Parent after having had the stroke)
- POS Parent description_Health (Comments about the health of the Parent and their deficits after having had the stroke)

Predispositions (PD) to caregiving
- PD to caregiving_CG-related (Comments about taking on the caregiving role for reasons that relate to the personal characteristics of the caregiver; e.g., duty, obligation, fit to the role, etc)

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- PD to caregiving _Parent-related (Comments about taking on the caregiving role for reasons that relate to the personal characteristics of the Parent)
- PD to caregiving _Situational (Comments about taking on the caregiving role for reasons that relate to the work, family, social and cultural context the caregiver is embedded in; e.g., there was no one else)

CG duties
- CG duties _Instrumental
  - CG duties _Instrumental_Household (Comments about the adjustments the caregiver made to the household where the parent is residing—i.e. handlebar installment)
  - CG duties _Instrumental_Appointments (Comments about making appointments for the Parent or taking them to their appointments)
  - CG duties _Instrumental_Diet (Comments about the parent’s dietary adjustments or feeding of the parent)
  - CG duties _Instrumental_Assistance (Comments about assisting the parent with ADLs, IADLs or arranging services for the parent – i.e. home care and social groups)
- CG duties _Emotional
  - CG duties _Emotional_Motivation (Comments about keeping Parent motivated and encouraging them)
  - CG duties _Emotional_Parental well being (Comments about ensuring that parent is safe, independent, happy, etc...)
  - CG duties _Emotional_Social (Comments about caregiver getting parent involved in social activities (i.e. getting out of the house, support groups, day trips))

Facilitators of caregiving (Aspects of the situation that make caregiving easier)
- Facilitators of caregiving _CG-related (Comments about personal characteristics of the caregiver or caregiving abilities that make caregiving easier)
- Facilitators of caregiving _Parent-related (Comments about personal characteristics of the Parent that make caregiving easier)
- Facilitators of caregiving _Situational (Comments about the work, family, social and cultural context that make caregiving easier)

Hindrances to caregiving (Aspects of the situation that make caregiving more difficult)
- Hindrances to caregiving _CG-related (Comments about personal characteristics of the caregiver or caregiving abilities—i.e. questioning abilities—that make caregiving harder)
- Hindrances to caregiving _Parent-related (Comments about personal characteristics of the parent that make caregiving harder)
- Hindrances to caregiving _Situational (Comments about the work, family, social and cultural context that make caregiving harder)
Impact of caregiving (Impact – positive and negative)

- Impact_Lifestyle consequences
  - Impact_Lifestyle conseq_Work (Comments about changes in the caregiver’s employment arrangements as a result of caregiving)
  - Impact_Lifestyle conseq_Family (Comments about changes in the caregiver’s family life as a result of caregiving)
  - Impact_Lifestyle conseq_Social (Comments about changes in the caregiver’s social life as a result of caregiving)
  - Impact_Lifestyle conseq_Living (Comments about changes in the caregiver’s living arrangements or lifestyle as a result of caregiving)
  - Impact_Lifestyle conseq_Priorities (Comments about how the caregiver’s priorities have changed or how they prioritize differently as a result of caregiving)

- Impact_CG health consequences
  - Impact_CG health conseq_Emotional (Comments about the caregiver’s feelings about the parent’s stroke event and taking on and performing the caregiving role)
  - Impact_CG health conseq_Physical/somatic (Comments about the caregiver’s physical condition and upon taking on and performing the caregiving role)
  - Impact_CG health conseq_Psychological resources (Comments about the psychological resources the caregiver draws upon as they take on and perform the caregiving role)

Relationships (R)

- Pre-stroke (PRS) Relationship
  - R_PRS_CG-Parent type (Comments that entailed a direct characterization or description of the type of relationship between the CG and Parent before the stroke)
  - R_PRS_CG-others (Comments about the CG’s relationships with other people such as their other parent, spouse, children, friends before the stroke)
  - R_PRS_Influence of CG-Parent (Comments about how the pre-stroke relationship between the CG and Parent has influenced the CG’s experience)
  - R_PRS_CG-siblings (Comments about the pre-stroke relationship between the caregiver and their sibling(s))
  - R_PRS_Sibling-Parent (Comments about the pre-stroke relationship between the CG’s siblings and the parent)
  - R_PRS_Parent-other (Comments about the pre-stroke relationship between the Parent and others)

- Post-stroke (POS) Relationship
- R_POS_CG-Parent type (Comments that entailed a direct characterization or description of the type of relationship between the CG and Parent after the stroke)
- R_POS_CG-others (Comments about the CG’s relationships with other people such as their other parent, spouse, children, friends after the stroke)
- R_POS_Influence of CG-Parent (Comments about how the post-stroke relationship between the CG and Parent has influenced the CG’s experience)
- RPRS_CG-siblings (Comments about the post-stroke relationship between the caregiver and their sibling(s))
- RPRS_Sibling-Parent (Comments about the post-stroke relationship between the CG’s siblings and the parent)
- RPRS_Parent-other (Comments about the post-stroke relationship between the Parent and others)

Support to caregiver from others
- Support to CG_Received:
  - Support to CG_Received_Instrumental (Comments about the instrumental support the caregiver received and the source of support – i.e. training from health care professionals (HCP), adjustments to parent’s household done by sibling, mobility aids given to parent by HCPs)
  - Support to CG_Received_Emotional (Comments about the emotional support the caregiver received and the source of support)
  - Support to CG_Received_Informational (Comments about the informational support the caregiver received and the source of support)
  - Support to CG_Received_Respite (Comments about the respite the caregiver received and the source of respite)
- Support to CG_Needed:
  - Support to CG_Needed_Instrumental (Comments about the instrumental support the caregiver needed but did not receive)
  - Support to CG_Needed_Emotional (Comments about the emotional support the caregiver needed but did not receive)
  - Support to CG_Needed_Informational (Comments about the informational support the caregiver needed but did not receive)
  - Support to CG_Needed_Respite (Comments about the caregiver’s need for respite)

Existential realizations (Comments about the caregiver or others’ awareness of death, uncertainty and fragility of life)

Health care system (HCS)
- HCS_Difficulties (Comments about the difficulties that the caregiver, parent or family faced while interacting with the health care system in the acute, rehab or community setting)
- **HCS_Positives** *(Comments about the positive experiences that the caregiver, parent or family encountered while interacting with the health care system in the acute, rehab or community setting)*
- **HCS_Improvements**
  - HCS_Improvements_CG *(Comments about the improvements that could be made in the health care system that would benefit the CG)*
  - HCS_Improvements_Parent *(Comments about the improvements that could be made in the health care system that would benefit the parent)*
- **Time**
  - Time_not enough *(Comments about the caregiver’s time being limited)*

**Miscellaneous** *(Comments that could not categorized into other codes)*

**Quotes** *(Pieces of transcript that may lend themselves to manuscript)*