

Caregiver Stress: An Exploration of Stressors and Coping Strategies Among Young Carers

Cayleigh Sexton, BA (Hons), B.Ed

Department of Child and Youth Studies

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Faculty of Social Sciences, Brock University

St. Catharines, Ontario

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Abstract

Young carers (YCs) are children and youth who take on extra responsibilities within their home due to a family member having a physical disability, chronic illness, mental health issues, addiction issues, or parental absence (Aldridge & Becker, 1993; Charles, Stainton, & Marshall, 2008; Stamatopoulos, 2015). YCs may experience increased stress levels and negative psychosocial outcomes due to their caregiving role (Charles et al., 2008; Collins & Bayless, 2013; Frank, Tatum, & Tucker, 1999; Lakman & Chalmers, 2018; Sahoo & Suar, 2010). **Objective:** This study sought to identify key stressors and coping strategies used by YCs and to determine if coping can moderate the relation between stress and negative outcomes. **Methods:** A sample of 58 YCs completed self-report questionnaires on stress, coping, self-esteem, depressive symptoms, anxiety, and loneliness. **Results:** YCs most frequently cited stressors related to recognition of their YC role within and outside of their family. Other stressors included school impacts and social impacts. YCs most frequently used disengagement coping strategies (e.g., wishful thinking or social withdrawal) and less frequently used engagement coping strategies (e.g., problem solving or seeking social support). The results revealed coping did not moderate the relation between stress and the examined negative outcomes within this sample. **Implications:** The results suggest the need for recognition and validation for YCs and the development of coping skill development programs so that YCs can learn how to cope using more proactive ways such as problem solving and seeking social support.

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CHAPTER ONE: INTRODUCTION

In Canada, an estimated population of 1.18 million children and youth are referred to as young carers (YCs; Stamatopolous, 2015). YCs are children and youth under the age of 25 who take on extra responsibilities and offer unpaid support to a family member (e.g., parent, sibling, or grandparent) because of physical disability, chronic illness, parental absence, mental health, or substance abuse issues (Aldridge & Becker, 1993; Charles, Stainton, & Marshall, 2008; Stamatopoulos, 2015). Research has demonstrated that YCs experience additional stress and negative outcomes due to this role (Charles et al., 2008; Collins & Bayless, 2013; Frank, Tatum, & Tucker, 1999; Lakman & Chalmers, 2018; Sahoo & Suar, 2010). Research is needed to understand what causes YCs stress and how coping plays a role in the outcome.

Because limited research focuses on YCs and caregiving stress, it is critical to examine the adult caregiving literature to aid in understanding the impact of caregiving. The constant demands of the caregiving role (referred to as caregiver burden) often result in social burden (isolation or life disruption), physical consequences (physiologic responses—i.e., stress hormone levels, physical illness), emotional consequences (worry, uncertainty), and psychological consequences (i.e., depression or anxiety; Cohen, Cook, Kelley, Sando, & Bell, 2015; Mausbach et al., 2012; Schulz & Sherwood, 2008; Warren, 2007). Adult caregiving research has identified several factors (known as moderators) that have an influence on the relation between caregiver stress and the above negative outcomes. These moderators include length of time caregiving, amount of social support, and levels of self-efficacy (Aldridge & Becker, 1993; Mausbach et al., 2012; Schulz & Sherwood, 2008; Tang, Jang, Lingler, Tamres, & Erien, 2015). Given that YCs are in the same role but at a different developmental stage than adults, it is important to

understand what may moderate YC stress and negative outcomes associated with caregiving in order to decrease the additional stress associated with the YC role.

Coping strategies can be an effective way to manage stress. How individuals cope with a stressor can determine the outcome (Lazarus & Folkman, 1984). Within adult populations, coping has been shown to be a valuable tool to decrease the negative impact of caregiver stress and has been shown to be an important predictor in the reduction of psychological caregiver stress (Garcia-Alberca et al., 2012). Specifically, interventions that help caregivers develop positive coping skills, such as problem solving, seeking support, and acceptance, have been shown to decrease caregiver burden, minimize negative psychosocial outcomes, and increase the use of positive coping skills among adults (Chen, Huang, Yeh, Huang, & Chen, 2015, Garcia-Alberca et al., 2012).

The purpose of this research study is to identify the key stressors of the caregiving role within the YC population as well as the coping strategies most frequently used by YCs. Further, this research aims to understand if and which type of coping strategies can assist in minimizing negative stress-related outcomes. This research expands the current understanding of the YC role and how negative psychosocial outcomes of caregiving stress can be reduced. This study addressed literature gaps and may also inform coping skill development programs designed to minimize the negative outcomes associated with the caregiver role.

CHAPTER TWO: LITERATURE REVIEW

This chapter provides an overview of the current literature and identifies gaps in the research that the current study addressed. Literature related to the YC context, the stress and coping framework that guided this study, and previous literature related to YCs' stress and coping will be explored. This chapter concludes with the study's three key research questions.

Young Carer Context

As previously mentioned, YCs are children and youth under the age of 25 who take on extra responsibilities and offer unpaid support to family members (Aldridge & Becker, 1993; Charles et al., 2008; Stamatopoulos, 2015). The support can include various tasks such as domestic chores, emotional support, and personal and general care (Frank et al., 1999; Warren, 2007). Domestic chores include tasks such as cleaning and cooking full meals for the family. Emotional support involves keeping the care recipient company, their spirits up, or bringing them to social gatherings or for a walk. Personal care tasks are dressing, bathing, giving medication, and helping with eating and drinking may be involved. General care tasks often focus on financial paperwork or transportation to the doctor or hospital. In comparison to non-caring children and youth, YCs spend up to 75% more time on a weekly basis on these types of tasks than non-caring children and youth (Aldridge & Becker, 1993; Warren, 2007).

In order to understand YCs, it is important to discuss the continuum of care within the YC population (Becker, 2007). The continuum of care suggests there is a range between a light and a very heavy end of caregiving that demonstrates the level of responsibilities YCs contribute to their families. As Figure 1 demonstrates, both the level of responsibilities as well as the number of hours providing care increases as YCs move along the continuum of care. The increased time spent on these responsibilities and tasks can lead to different experiences than

those had by their non-caring peers and contribute to feelings of isolation, loneliness, depression, lower self-esteem, and increased stress (Charles et al., 2008; Collins & Bayless, 2013; Frank et al., 1999; Lakman & Chalmers, 2018; Sahoo & Suar, 2010).

'Light end' (low levels of caregiving and responsibility)	→ → → → → → 'Heavy end'		'Very heavy end' (high levels of caregiving and responsibility)
'Routine' levels and types of caregiving including some help with Instrumental Activities of Daily Living	→ → → Caregiving tasks and responsibilities increase in amount, regularity, complexity, time involved, intimacy and duration		'Substantial, regular and significant' caregiving including considerable help with Instrumental Activities of Daily Living
Household tasks and caregiving tasks can be considered age and culturally appropriate for the child's age			Household tasks and caregiving tasks can be considered age and culturally inappropriate for the child's age
Most children			Few children
	Young carers providing 0–19 hours of care per week	Young carers providing 20–49 hours of care per week	Young carers providing 50+ hours of care per week
Many 'hidden' young carers (unknown to service providers)			

Figure 1. Becker's (2007) continuum of care.

Individual members of a family do not all assume equal responsibilities for caregiving. Age, gender, birth order, and individual factors are considered possible explanations for these within-family differences. Research suggests that the average age of being a YC is 12 (Nag-Cupal, Daniel, Koller, & Mayer, 2014; Shifren & Kachorek, 2003; Warren, 2007); however, it has been shown that children as young as 5 are providing care (Aldridge & Becker, 1993). Although gender may not be a determining factor in who provides care, contrary to gender role

expectations (Lakman & Chalmers, 2018; McDonald, Cumming, & Dew, 2009), some researchers have found that females become the caregiver specifically in regards to domestic and personal care activities (Eley, 2004; Joseph, Becker, Becker, & Regal, 2009). Smyth, Blaxland, and Cass (2011) in turn suggested that gender may play a role; they found that if males took on caregiving roles within their family, they did not share this information with others as it contradicted social norms of masculinity and may contribute to a negative judgment of them within society.

Regarding birth order, it is unclear within YC literature if this factor plays a role in determining caregiver responsibilities. Contrary to an expected birth-order effect where the eldest would assume sole caregiving responsibilities, studies have not supported this expectation (Lackey & Gates, 2001; Synes-Taraba, 2008). Finally, temperament and personality may contribute to differences in family caregiving responsibilities. Researchers have hypothesized that certain temperament and personality traits—such as having a more optimistic attitude—could lead YCs to be more likely to want to help their family members and take on more responsibility for them (McDonald et al., 2009; McDonald, Dew, & Cumming, 2010; Sahoo & Suar, 2010). Limited research has explored temperament differences among YCs compared to non-carers but there is some research showing temperament differences where YCs had higher activity levels, higher withdrawal, lower flexibility, and lower cheerfulness than non-carers (Lakman, 2015; Lakman & Chalmers, 2018). Each of these factors could contribute to family member differences in caregiving responsibilities within the home and to differing levels of stress, coping strategies used, and the ability to cope with the stress of caregiving.

Having supports around the family may reduce the amount of caregiving required by children and youth and therefore reduce the associated stress of caregiving. Research has

revealed that compared to non-caregiving peers, YCs lived more frequently in single-parent homes, received less extended family support, and had lower levels of attachment to their mothers, fathers, and friendship quality when compared to non-caregiving peers (Lakman, 2015; Lakman & Chalmers, 2018). Research also suggests that YCs keep their caregiving role hidden from others (Aldridge & Becker, 1993; Rose & Cohen, 2010; Smyth, Blaxland, & Cass, 2011). One potential reason for the hidden nature of the YC role may be the contradiction between the traditional role of a child needing care by others versus a YC providing care for a parent or family member (Aldridge & Becker, 1993). Due to this contradiction, YCs may be more inclined to keep the caregiving role hidden for fear of judgment or repercussions from social services and therefore not receive social supports outside of the family unit (Smyth et al., 2011).

For adult caregivers, caregiving is an accepted responsibility and there are numerous formal and informal supports given such as respite care, home health care, individual and family counselling, as well as support groups (Robinson, Buckwalter, & Reed, 2013). When compared to adult caregiver supports, YC supports are rare. In Canada, Stamatopolous (2016) identified three formal programs available offering limited supports. Canada also has no formal policies that acknowledge YCs, whereas current policy acknowledges and supports adult caregivers (Government of Canada, 2017).

Stress and Coping Model

Current literature on stress and coping focuses on which coping strategy is most effective for different stressors (e.g. acute, sequences, intermittent, or chronic). Coping strategies (i.e., ways to reduce stress) have been shown to influence a negative stress outcome (Garcia-Alberca et al., 2012; Pakenham, Chiu, Bursnall, & Cannon, 2007; Sexton, Chalmers, & Lakman, 2018). This model is beneficial to use in the YC context as it creates a foundation of different forms of

stressors and the process of how individuals choose to cope depending on the type of stressor at hand. The process of this model may help understand the possible outcomes associated with the caregiving role. To understand the stress/coping interaction, it is important to understand the background of how the process works.

The Stress and Coping Model developed by Lazarus and Folkman (1984) is used to help understand the complex process in the relation between stress and coping. To begin, it is important to understand the different forms of stress addressed by this model. There are four broad types of stressors: (a) acute, time-limited stressors (e.g., awaiting surgery); (b) stressor sequences (e.g., divorce); (c) chronic intermittent stressors (e.g., family member with mental illness); and (d) chronic stressors (e.g., permanent disabilities; Lazarus & Folkman, 1984). The variety of stressors relate to the YC role as these examples may be the reason for care. For example, the YC may experience chronic stress as a result of a family member with a physical disability or an acute, time-limited stressor of a family member having a surgery. This model reflects the types of stressors that could contribute to the negative outcomes of being a YC.

While stress can be seen as normative, there is a two-step process (i.e., primary and secondary appraisal) in the Stress and Coping Model that evaluates the likelihood of the stressor interfering with daily function for the individual. The first step in the process is called primary appraisal and this step places the stressor within three categories: irrelevant, benign-positive, or stressful. If the stressor is categorized as irrelevant or benign-positive, then the individual does nothing as the stressor is not deemed stressful. However, if the stressor is categorized as stressful, he/she will further classify it as related to harm/loss, threat, or challenge (Lazarus & Folkman, 1984). Specifically, individuals consider if damage has already been done to

themselves (harm/loss), if harm or loss have not occurred but there is concern (threat), and if there is a potential for gain or growth (challenge).

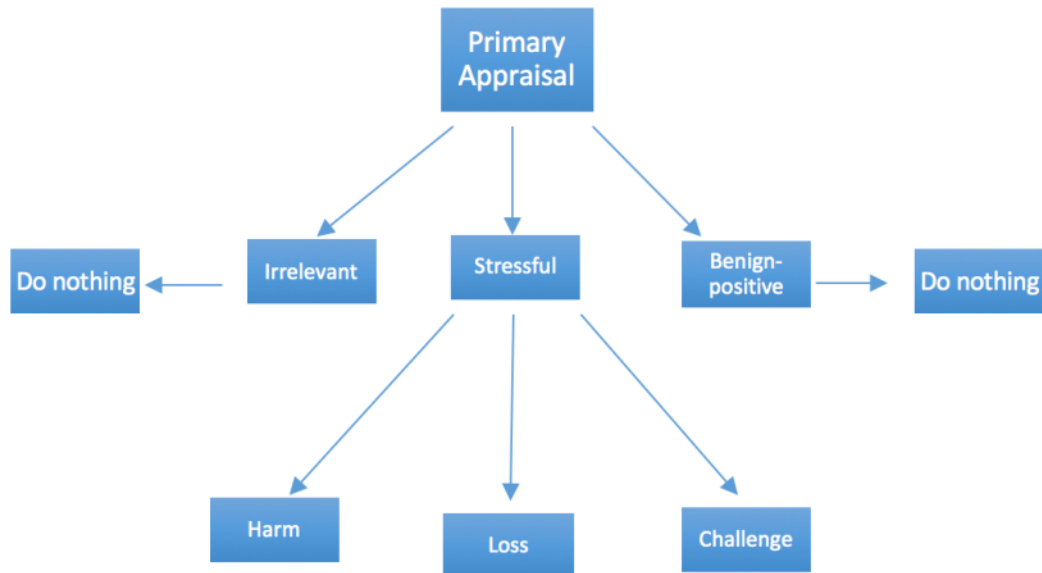


Figure 2. Stress and Coping Model: Primary appraisal (Lazarus & Folkman, 1984).

Secondary appraisal is how a stressful situation is appraised; in turn, this impacts the evaluation of what can be done to address the situation. This step evaluates what type of effective coping strategy could be used when accounting for the specific stressor identified as a threat. There are two main types of coping strategies: problem-focused coping and emotion-focused coping. Problem-focused coping targets direct coping strategies within the environment or within the self (Lazarus & Folkman, 1984). For example, this type of coping strategy could involve altering the environmental triggers of stress or making cognitive changes where the coping strategy would focus on the self to address the stressor. This could involve multiple skills including problem solving, cognitive restructuring, finding resources, and/or creating new procedures. The second form of coping strategy is emotion-focused coping, which typically is used with appraised environmental stressors where little to nothing can be changed to minimize

the stressor within the environment. Emotion-focused strategies usually are based on cognitive processes to decrease emotional distress for the individual. Examples of emotion-focused coping strategies include avoidance, minimization, distancing, selective attention, positive comparisons, and looking at positive value in negative events (Lazarus & Folkman, 1984).

The type of coping strategy selected depends on whether individuals feel they can “fix” the problem or, if not, whether emotion regulation may be a better form of coping (Lazarus & Folkman, 1984). If the stressor is identified as “fixable,” problem-focused coping, such as generating alternative solutions, will be used. In contrast, if the stressor is identified as something that is not able to be relieved or fixed, emotion-focused coping strategies that focus on emotional regulation of the individual (e.g., minimization) will be used.

Coping has been demonstrated in previous studies to make a difference between a positive or negative outcome in a stressful situation. Research suggests the use of problem-focused coping skills and engagement coping skills (i.e., problem solving, expressing emotions) were associated with more positive outcomes such as decreased caregiver burden (Chen et al., 2015; Garcia-Alberca et al., 2012). In the context of caregiver burden, emotion-focused coping has also been shown to protect caregivers from developing higher anxiety levels in the future (Cooper, Katona, Orrell, & Livingston, 2008). Furthermore, disengagement or dysfunctional coping strategies (i.e., problem avoidance, wishful thinking) were associated with increased levels of anxiety and depression (Cooper et al., 2008; Garcia-Alberca et al., 2012). Research has therefore shown the power of coping strategies and how they can decrease the negative outcomes associated with the caregiving role.

In sum, there are two main functions of coping; the first function is to strategically select a coping strategy to address that stressor. The second function relates to the outcome of the

coping strategy used—that is, the effectiveness of the coping strategy on the outcome associated with that specific stressor. This creates a direct pathway from stressors to coping strategy to physical and psychosocial outcomes. The variance in outcomes has been linked to the way individuals cope with stressors (Lazarus & Folkman, 1984).

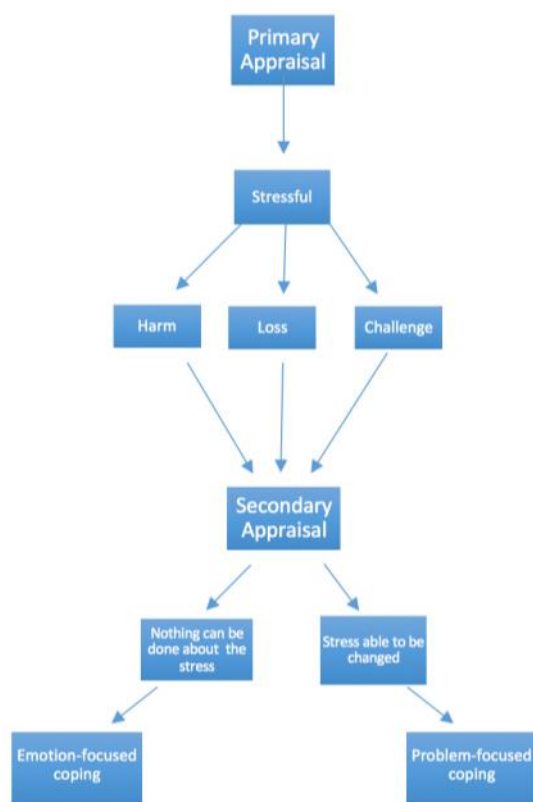


Figure 3. Stress and Coping Model: Full process (Lazarus & Folkman, 1984).

Caregiver Stress

Stress can come from many sources, but the stress from caregiving shares characteristics of chronic stress as it can create physical and psychological consequences over time. The effects can even continue after no longer providing care (Frank et al., 1998; Schulz & Sherwood, 2008). Stress related to the caregiving role can also be impacted by the unpredictability and varying levels of control within the situation. The varied caregiving requirements can lead to periods of

heightened stress that can impact other parts of caregivers' lives such as family, school, work, or their social life (Cohen et al., 2015; Schulz & Sherwood, 2008).

Adult caregiver literature has been explored as there little research that has been conducted on YC stress and how it impacts caregivers. Within adult caregiving research, Llanque, Savage, Rosenberg, and Caserta (2016) refer to stress experienced by caregivers as "caregiver stress." This concept has been studied to understand the complexity of the term "stress" within the caregiver context. Llanque et al. (2016) defined caregiving stress as "the unequal exchange of assistance among people who stand in close relationship to one another, which results in perceived tension and fatigue on the caregiver" (p. 28). These types of exchanges of assistance can be related to physical tasks, emotional support, or medical support (Cohen et al., 2015; Frank et al., 1999; Schulz & Sherwood, 2008; Warren, 2007). Along with caregiver stress there is also the term "caregiver burden" in which the demands on the caregiver can leave them feeling burdened with the tasks and responsibilities, but are necessary for the care-recipient to function (Llanque et al., 2016). The burden associated with caregiver stress has been linked with physical, emotional, and psychological consequences.

As noted, there are many different physical, emotional, and psychological consequences of caregiving stress in the adult population. Physical consequences may include injuries from lifting, increased blood pressure and heart rate, as well as increases in various stress hormones (Schulz & Sherwood, 2008; Warren, 2007). Emotional consequences may result from the inability to participate in social interactions or functions with friends or the difficulty in leaving the house due to the caregiving role (Cohen et al., 2015; Llanque et al., 2016; Thomas et al., 2003; Warren, 2007). The importance of social activities and interaction is clear in research as it suggests that caregivers who participated in social activities have less social burden (Cohen et

al., 2015). Researchers are now focusing on understanding the psychological consequences of adult caregiver stress. Currently, caregiver stress research predominantly focuses on the relation between stress and depression and anxiety. Research has established a clear link between caregiver stress and depression and anxiety (Ferrara et al., 2008; Gonzalez-Salvador, Arango, Lyketsos, & Barba ;1999; Hayslip, Han, & Anderson, 2008; Mausbach et al., 2012; Tang et al., 2015). This demonstrates a need for further research focusing on other psychosocial outcomes related to caregiver stress.

Although research is limited within the field of YCs and stress in the Canadian context, Sexton et al. (2018) identified the most frequently selected normative stressors that were not specific to the caregiving role, such as daily hassles (e.g., deciding what to wear). The stressors that were most frequently selected were stressors such as getting up in the morning, not enough sleep, and not having enough time. It is interesting to note here that these stressors could just be normative stressors but also could be directly linked to the YC role (Sexton et al., 2018). These results give us a glimpse of the types of stressors that are part of YCs' lives.

As stress is evident within a caregiver role, it is essential to understand what characteristics of an individual or environment can moderate the negative effects of the role. Three main characteristics have been shown to be critical in understanding the outcomes of caregiver stress. The first is the intensity and duration of caregiving, as it has been shown to be an important factor in determining the impact of the caregiving role (Aldridge & Becker, 1993; Schulz & Sherwood, 2008). Gonzalez-Salvador et al. (1999) found that adult caregivers of Alzheimer's patients showed higher levels of stress and psychological morbidity (e.g., somatization, depression) than non-carers; however, the higher levels of psychological morbidity was partially explained by the length of time spent caring. This demonstrates how the length and

time spent caring contributes to the association between caregiving stress and the well-being of the caregiver.

The second key factor is self-efficacy—the confidence the caregiver has to complete the required tasks within the role (Tang et al., 2015). The likelihood of self-efficacy making a difference in the levels of stress depends on how the stressors are appraised. How the stressor is appraised could then decrease the level of confidence if appraised as not manageable. Thus, the more confident that caregivers are in their ability to be caregivers, the less stressed they will feel and this may lead to lower levels of depressive symptoms (Tang et al., 2015).

The third key factor in reducing the impact of caregiver stress is the amount of social support available to the caregiver. Mausbach et al.'s (2012) study of caregivers of Alzheimer's patients demonstrated how caregiving stress decreased personal resources, such as positive coping strategies, which in turn increased maladaptive responses to stress. Hayslip et al. (2008) also found that perceived social support was a key predictor of stress in caregivers of Alzheimer's patients. Further, Hayslip et al. found that merely knowing that social support was available lowered feelings of depression and somatic anxiety. The fact of knowing social support was available also increased life satisfaction for caregivers. Overall, these studies demonstrate the importance of social support and how it can minimize the negative psychosocial outcomes associated with stress.

As clearly demonstrated, caregiver stress has been linked with many negative outcomes. Three key factors have been shown to help decrease the negative impact of caregiver stress: length of caregiving, self-efficacy, and amount of social support available. It is critical to understand how these factors may also impact YCs' stress levels. As there is limited research targeting YCs, it is important to develop a concrete understanding of the adult literature and then

explore what research is available on YCs, stress, and psychosocial outcomes. For example, Frank et al. (1999) found that length of time spent caregiving impacts the psychological well-being of YCs. If the caregiving role begins early in life it may be compounded with the developmental needs of a child, who will need to develop different knowledge and skills (Aldridge & Becker, 1993).

The second factor is self-efficacy, and research has found that because the YC role is not seen as normative for a child, it may lead to decreased levels of self-efficacy. Because their role is not validated by those around them, YCs may lack confidence and feel insecure in their role (O'Dell, Crafter, de Abreu, & Cline, 2010; Smyth et al., 2011). Such feelings of insecurity in relation to being able to care for their ill family member has been shown to increase the likelihood of depression and anxiety symptoms among YCs (Sahoo & Suar, 2010).

Furthermore, when discussing the third factor, available social supports, it is less likely YCs would be able to access support due to the hidden nature of the caregiving role. Often YCs do not discuss with anyone the role that they have at home. This could be due to the contradictions of their role as a child acting in a traditionally adult role, as they are caring for their family members rather than parents solely caring for the YC (O'Dell et al., 2010; Smyth et al., 2011). YCs also fear the intervention of family and children services if they share their caregiving role with others (Smyth et al., 2011).

It is also critical to point out the lack of social support available for YCs, so even if YCs were willing to share with others about their caregiving role, there is limited access to YC-specific supports in Canada. Currently, there are only two active YC support programs in Canada for more than 1.18 million YCs who may need these supports (Stamatopoulos, 2015, 2016). In comparison, adult caregivers tend to have more access to social supports, such as respite care,

home health care, and support groups when compared to the two YC support programs (Robinson et al., 2013; Stamatopoulos, 2016). The research cited throughout this section has been quite conclusive when looking at the negative consequences due to caregiver stress in the adult population, and raises the following question: If these are the negative consequences for adults, what could be the potential amplification of consequences for children and youth within the same role?

Young Carer and Psychosocial Outcomes

The literature on adult caregiving provides the foundation for potential burden and increased stress levels as outcomes, due to the daily tasks of a caregiver. It demonstrates that there is a lot of time and care involved, and this can have negative impacts on the caregiver if there is not enough support (Cohen et al., 2015; Schulz & Sherwood, 2008). The following section considers how the increased levels of stress and responsibilities might impact a child or young person within the same type of caregiving role.

Changes in health, ability, or diagnosis initiates change within the family. This can lead to roles being adapted and finding someone to step up in order for the family to function. In some cases it is the child or young person within the family who has to take on the extra responsibilities within the home, and that is who we refer to as a YC. The role of a YC is usually not a choice (Bolas, Van Wersch, & Flynn, 2007) but rather a necessity for the family to function after that initial change occurs. Along with this caregiving role comes increased levels of stress and responsibilities, which due to the change in family roles can decrease the YC's self-esteem as it creates restrictions socially and academically (Banks et al., 2002). The stress due to the caregiving role can also increase the likelihood of depression and anxiety, while YCs are also worrying about their future (Aldridge & Becker, 1993; Sahoo & Suar, 2010). The extra

responsibilities and tasks that YCs take on often do not fit into the typical “child” role and can make it difficult for YCs to share their experiences with others and seek social support (Bolas et al., 2007). YCs’ hidden role can make them feel lonely and isolated from those around them (Bolas et al., 2007; Frank et al., 1999; Moore, McArthur, & Morrow, 2009). YCs are at risk for experiencing depression, anxiety, loneliness, and self-esteem issues, but they still have the challenges of developing into an adult (Bolas et al., 2007). Within the caregiving role, YCs experience many negative and positive effects but it is imperative to understand the complexities of each psychosocial outcome to know how to help promote a more positive outcome.

Self-Esteem

Self-esteem is built upon personal evaluation and social interactions (Frant, 2016; Kumar & Raja, 2009). Within the YC role, social interactions outside of the home are often limited due to the demand of YCs’ responsibilities. Social interactions are very important during middle childhood and adolescence as they provide an opportunity to build self-esteem with peers, teachers, and community members (Collins & Bayless, 2013). Therefore, the lack of social interaction can lead to lower levels of self-esteem, especially when compounded with changes in family roles. YCs may have insecurity within their caregiving role due to the changes within the family. This may lead them to feel conflicted with their role as a child and a “carer” (Earley, Cushway, & Cassidy, 2007; Rose & Cohen, 2010). Previous research suggests that YCs often feel invalidated in their role as a child and their role as a carer, which can further decrease their level of confidence in their ability to fulfill all of their caregiving responsibilities (Rose & Cohen, 2010). Research has also revealed that some YCs put all their energy and time into their caring role to avoid dilemmas or conflicts between their competing roles as a child and carer who has adult responsibilities (Earley et al., 2007; Rose & Cohen, 2010). Therefore, the research

suggests the conflict of YCs' various roles can affect their levels of self-esteem and can inhibit their confidence in being the carer in the family.

Research has demonstrated that the caregiving role can impact self-esteem (Banks et al., 2002; Bolas et al., 2007; Collins & Bayless, 2013; Lakman, 2015). Whether the impact is positive or negative depends on if YCs created a positive view of their role; if the YCs gained feelings of usefulness and capability through their caregiving role, this was then associated with positive self-esteem (Bolas et al., 2007). In contrast, other research has demonstrated that compared to non-YCs, YCs have lower self-esteem, lower life satisfaction, and a less positive attitude (Banks et al., 2002; Collins & Bayless, 2013; Lakman, 2015).

Collins and Bayless (2013) compared YCs to non-YCs on life satisfaction and self-esteem. They found that YCs have significantly lower levels of life satisfaction and self-esteem. However, the YCs' levels of self-esteem were still in the "normal" category. Therefore, YCs did have significantly different levels of self-esteem from their peers, but their self-esteem levels in that study would not be classified as "low self-esteem." Banks et al. (2002) in turn found that YCs had significantly lower levels of self-esteem. The levels of self-esteem did not change even if there were increased levels of responsibilities or tasks in the home. Lakman (2015) further replicated these results and found YCs had significantly lower levels of self-esteem when compared to non-YCs. It is important to point out that although the levels in each study are significantly lower than their non-YC peers, it is not clear if YCs would be classified as having low self-esteem (Banks et al., 2002; Collins & Bayless, 2013; Lakman, 2015). Further, the research by Bolas et al. (2007) demonstrates a way to improve self-esteem could be allowing YCs to feel a sense of achievement and capability in order for the YC to see their caregiving role in a more positive way.

Depression

The literature on adult caregiving shows that depression is one of the most frequently researched consequences of caregiving (Ferrara et al., 2008; Gonzalez-Salvador et al., 1999; Hayslip et al., 2008; Mausbach et al., 2012; Tang et al., 2015). Within YC research, the relationship between the caregiving role and depression has shown mixed results. Pakenham, Chiu, Bursnall, Cannon, and Okachi's (2006) study illustrated the uncertainty of the relationship, finding no differences in depression levels when YCs and non-YCs were compared. However, Lakman (2015) found that YCs experience higher levels of depressive symptoms compared to their non-YC peers. These studies show the inconsistency in the results regarding depressive symptoms in the YC population. A different study by Sahoo and Suar (2010) focused on doing a content analysis of YCs' stories. The authors found that YCs expressed more internal needs and external pressures due to their level of emotional and domestic care to their ill family members. Further, the ill family environment brought about insecurity for the YCs about their caregiving role, which lead the YCs to feel low and depressed.

Although the results are mixed, it still demonstrates the pressures that come along with extra responsibilities. It is imperative to understand the long-term implications young caregiving can have on mental health. This is evident as the time spent caregiving and the parent-child relationship have been linked with mental health as an adult (Shifren & Kachorek, 2003). This is why it is critical to understand this complex relation between the caregiving role and depression, so that the negative impacts do not follow the YC into adulthood.

Anxiety

Within the caregiving role, anxiety is typically associated with worry for the care recipient, rather than anxiety for the YCs themselves (Earley et al., 2007; Sahoo & Suar, 2010;

Thomas et al., 2003). Earley et al. (2007) found that YCs have a hard time turning off their responsibilities, therefore YCs may experience feelings of anxiety when they are away from the care recipient. Sahoo and Suar (2010) confirm anxiety as one of the key pressures and identified increased levels of anxiety for YCs compared to non-YCs. YCs also expressed worry about the future, as the caregiving role can be inconsistent and unpredictable (Sahoo & Suar, 2010). The inconsistency and unpredictability also relates to the hidden nature of the role, as there is fear that YCs will be taken away from their role within the family if others find out (Earley et al., 2007; Rose & Cohen, 2010).

Research also suggests that YCs often fully immerse themselves in the YC role so that they can reduce these feelings of anxiety, but this can further isolate them socially (Rose & Cohen, 2010). This allows YCs to not have conflict from other priorities such as school or work, but rather to focus fully on their responsibilities. However, another cause of anxiety for YCs is the transition into adulthood, which relates to how the YC understand themselves and their own identity outside and within their caregiver role (Earley et al., 2007). This could pose another conflict for YCs if they have fully immersed themselves in the YC role and may not be able to see themselves outside of the role. All of these challenges of the caregiving role and how the YC chooses to adapt can create immense pressure and lead to further worry and anxiety. This can in turn lead to difficulties in their social and emotional development.

Loneliness/Isolation

Within the YC literature the focus is more on the social isolation of the caregiving role rather than actual loneliness. However, there are clear connections between being socially isolated and being lonely. This is clearly evident as YCs often feel invisible, invalidated, and excluded by those around them (Rose & Cohen, 2010). This is further amplified as YCs find it

hard to make and keep friends due to the amount of time spent caring and the lack of understanding of their role (Moore et al., 2009). YCs have reported that it can be easier to conceal their role and responsibilities, rather than expect others to understand their family situation (Bolas et al., 2007). The lack of understanding can lead to YCs being socially isolated and excluded due to peer rejection and a lack of awareness (Moore et al., 2009). This demonstrates the prominent theme of social isolation and exclusion due to the caregiving role.

Although the research on YCs and loneliness is limited, Nagl-Cupal et al. (2014) looked at levels of loneliness and found that 23.6% of YCs said they preferred to be alone, while only 16.9% of non-YCs preferred to be alone. This does show a difference in the YCs' preference to being alone compared to their peers. There have also been conflicting results, as a study by Lakman (2015) found no differences in levels of loneliness in YCs when compared to their non-YC peers. The research results given in this section point to the need for more research to understand if YCs are lonely or if they just prefer to be alone.

Many of the studies related to YCs found negative impacts of the caregiving role including increased stress, lower self-esteem, depressive symptoms, anxiety, and loneliness (Charles et al., 2008; Collins & Bayless, 2013; Frank et al., 1999; Lakman & Chalmers, 2018; Sahoo & Suar, 2010). However, it is important to note that there have been positive skills that can come from the caregiving role, including maturity and life skills (Aldridge & Becker, 1993; Pakenham et al., 2006). It is clear that a positive attitude and YCs feeling a sense of achievement and capability can help YCs see their caregiving role in a more positive way. One of the key factors that may allow YCs to view their caregiving role in a positive way is how they cope with the daily stressors associated with their role. The difference between a positive and negative outcome can be the way the stressor is perceived, and how the individual chooses to cope with that stressor (Lazarus & Folkman, 1984).

The Role of Coping

Stress clearly has been shown to cause negative impacts within the YC role. Caregiver stress and burden can cause increased levels of depressive symptoms, anxiety, loneliness, and decreased self-esteem (Charles et al., 2008; Collins & Bayless, 2013; Frank et al., 1999; Lakman & Chalmers, 2018; Sahoo & Suar, 2010;).

Coping is a key factor that can make a difference in the way an individual reacts to a stressor which can then be linked to specific outcomes. Coping has been called one of the most important predictors within the context of caregiver psychological distress (i.e. depression/ anxiety) and adjustment outcomes—that is, positive affect and life satisfaction (Garcia-Alberca et al., 2012; Pakenham et al., 2007). The many different categories of coping strategies creates a challenge in comparing effective coping strategies between studies. The research clearly indicates that certain types of coping strategies are more effective depending on the stressor and outcome. Although each of the five studies described below have different categories of coping strategies, they each help to build a foundation regarding the coping strategies that can be taught to decrease caregiver burden and negative outcomes associated with the role (Chen et al., 2015).

Within the literature on adult caregiving stress, Garcia-Alberca et al. (2012) looked at the mediating role of coping strategies between the relation of caregiver burden and depression and anxiety. The authors looked at two categories of coping: (a) engagement strategies, which included problem solving, cognitive restructuring, expressing emotions, and social support; and (b) disengagement strategies, which included problem avoidance, wishful thinking, self-criticism, and social withdrawal. The results suggest that it is the actual coping strategy used that creates a higher vulnerability to depression and anxiety rather than the caregiver burden itself (Garcia-Alberca et al., 2012). This is shown through the increase in anxiety and depression levels

when disengagement coping strategies were used and decreased levels in anxiety and depression when engagement coping strategies were used. This demonstrates that engagement strategies help eliminate negative outcomes because the individual is addressing the problem stressor. Such a form of coping allows the caregivers to have some control in adapting to the stressors that are evident within this role. The way an individual adapts to the stressor is through emotion regulation and problem solving to manage and help minimize the stressors. In contrast, disengagement coping strategies further isolates the caregiver from social support networks (Garcia-Alberca et al., 2012). The results from Garcia-Alberca et al.'s study illuminate the power of coping and how coping mechanisms mediate the outcomes caused by stress.

Chen et al. (2015) looked at coping in relation to the effectiveness of an intervention program among adult caregivers. The intervention program focused on developing effective coping strategies to decrease caregiver burden. The intervention focused on coping skill development of problem-focused and social support coping strategies. The measure subscales used five different forms of coping: problem-focused, seeking social support, blaming self, wishful thinking, and avoidance. These forms of coping were then categorized into positive and negative coping strategies. The study used a five-session intervention group and a control group which were then compared for levels of caregiver burden. The participants in the intervention group showed improvement in their use of positive coping strategies and a decrease in caregiver burden. The results of Chen et al.'s study show that coping strategy interventions can be beneficial and that positive coping can decrease caregiver burden.

Coping can be used differently within child populations. A longitudinal study by Evans et al. (2015) evaluated three different types of coping and if they can mediate the relation between stressful life events and levels of depression. The research focused on child participants at varied

risk levels. The children in the high-risk category had at least one parent who had a current Major Depressive Disorder (MDD). The children in the low risk category had parents who had no known psychological disorders. Evans et al. uncovered another layer by showing how stress affects children between the ages of 7 and 17 at varied risk. The three different types of coping were primary control (i.e., planning, seeking social support), secondary control (i.e., acceptance, positive reinterpretation), and disengagement (i.e., behavioural disengagement, denial). The results revealed a partial mediation for primary control and disengagement coping only, which was in relation to stressful events and depressive symptoms. Children in the low-risk category had increased disengagement coping and decreased primary control coping due to stressful life events. For the children in the high-risk category, no relation was found between disengagement coping or primary control coping and stressful life events. However, the level of risk for the child did not interfere with coping being a mediator between stress and depression (Evans et al., 2015). The results from Evans et al.'s study reveal that the way a child copes can decrease the relation between stress and depression symptoms. The results also infer stressful events can decrease effective coping and increase ineffective coping strategies for some children (Evans et al., 2015).

Further differences can be found when exploring stress and coping within the YC population. Pakenham et al. (2007) looked at the YC population and how different factors such as choice in caring, social support, stress appraisal, and coping can mediate the relation between global distress (i.e., depression, anxiety, somatization) and adjustment outcomes (i.e., life satisfaction, positive affect, benefits). The results from Pakenham et al.'s research allows exploration of a stress and coping model within the YC context. Pakenham et al. explored this model by using five main factors within the coping measure: problem solving, wishful thinking, acceptance, denial, and social support. Each of these factors was then placed into approach

coping (problem solving, social support, acceptance) or avoidant coping (wishful thinking, denial). The results revealed how coping is an important predictor in adjustment outcomes, which can mean higher positive outcomes and lower distress. Employing approach coping strategies more frequently (i.e., problem solving) was associated with better adjustment outcomes. Additionally, YCs' less frequent use of avoidant coping strategies (i.e., denial) was also associated with better adjustment outcomes (Pakenham et al., 2007). The results from Pakenham et al.'s study sheds light on the context of young caregiving and how social support and coping can lead to overall better adjustment and lower distress. The results lay the groundwork for further research to explore key stressors and coping strategies and how these can minimize negative outcomes.

Sexton et al. (2018) further explored the YC population and looked at how coping could decrease the relation between YC stress and negative psychosocial outcomes (i.e., depressive symptoms, social anxiety, self-esteem). Sexton et al. found that YCs most frequently used avoidance-focused coping strategies such as keeping busy, walking away, and doing nothing, whereas YCs used problem-focused coping strategies less frequently, such as talking to other people or getting rid of the problem. Further, results suggested that emotion-focused coping strategies were more effective between stress and both depression and self-esteem. In contrast, problem-focused coping strategies were more effective between stress and social anxiety (Sexton et al., 2018). The results from Sexton et al.'s study allows for a deeper understanding of the YC context and what coping strategies are being employed by YCs. The results also provide a glimpse into what types of coping strategies may be more beneficial for different psychosocial outcomes.

All of the research discussed in this section allows for a snapshot of how coping can be an effective tool to not only decrease negative outcomes, but also build skills such as emotion

regulation and problem solving. Each of these studies show how the adverse effects of stress can reduce the quality of coping strategies used within a caregiving context (Evans et al., 2015). However, more importantly, the study by Chen et al. (2015) informs the effectiveness of coping skill development interventions and shows that programs helping to build problem-solving and seeking social support can be beneficial in lowering distress and creating positive outcomes. This allows future research to be built on the knowledge that coping skill development does possess these types of qualities and can be taught to help mitigate the stress that is part of the daily tasks and responsibilities of YCs.

Gaps in the Research

The current research on caregiver stress and YC research point to a need for key areas of stress, coping, and psychosocial outcomes to be explored within the YC context. The limitation of research creates a gap in what is understood about YCs and how to better support them within the caregiving role. There are five main gaps within this research field.

The first of these is the knowledge about YCs in the Canadian context. Although there has been an increase in Canadian YC research in the last decade, more information is urgently needed to support the need for policy reform and to better support YCs. This is clear when comparing current policies and supports available in other countries, such as the United Kingdom. In the U.K., there is a substantial research base and national legal rights for YCs, who are systematically supported through dedicated services and interventions (Becker, 2007; Stamatopoulos, 2016). In comparison, in Canada there are no existing policies or legislation that support YCs and acknowledge them as a population. Canada does have limited policies in place for adult caregivers (such as tax reductions and compassionate leave) but YCs are left out of these policies (see Government of Canada, 2017). For example, there are only two active YC

support programs in Canada, both in Ontario, which has an estimated population of 482,929 YCs (Stamatopoulos, 2015, 2016)—even though Canada has an estimated population of 1.18 million YCs in need of support. This demonstrates the need for the current research as it is evident due to the large number of YCs within Canada how we need to better understand who YCs are and what they need in order to be supported.

The second main gap in the research correspond to the aspects of life that cause YCs stress. Previous research has demonstrated that YCs do experience increased levels of stress but there is minimal understanding on what types of stressors lead to these increased levels (Aldridge & Becker, 1993; Pakenham et al., 2007; Thomas et al., 2003). The current research will address this gap by using the Young Carers Perceived Stress Scale (Early, Cushway, & Cassidy, 2006). The items within the scale focus on key stressors related to the YC role and will therefore give a clearer view of the stress that comes from being within this role. If research can identify the main stressors YCs experience, then interventions and supports would be able to better address those specific stressors to help alleviate negative impacts.

The third main gap corresponds to such stressors and the types of coping strategies YCs use in their daily life. There are so many different forms of coping, yet previous research only provides limited information about what types of coping strategies that YCs typically use. The current research will address this gap by using the Coping Strategies Inventory (Tobin, Holroyd, & Reynolds, 1982), which focuses on the specific types of coping strategies; it has seven different subscales that allow a deeper understanding of the types of coping YCs are using.

The next logical gap would be to understand the relation between stress and different psychosocial outcomes. Previous research (e.g., Pakenham et al., 2007) typically focused on overall well-being or adjustment and does not break the outcomes down into specific outcomes

such as anxiety or self-esteem. The current research will allow for a strategic link from YC stress to four different potential psychosocial outcomes (depressive symptoms, anxiety, self-esteem, and loneliness). This will help explain the negative impacts of the YC role and how YC stress may be associated with each of these psychosocial outcomes. These results will explore what outcomes are actually associated with YC stress.

The final gap in research is the complex relation between stress, coping, and psychosocial outcomes. Scant research looks at the effectiveness of different forms of coping on specific psychosocial outcomes. The current research will address this gap by having 15 different models that look at each outcome separately (e.g., anxiety) to understand which type of coping (emotion-focused engaged, emotion-focused disengaged, problem-focused disengaged) may decrease the relation between YC stress and each of the psychosocial outcomes. This could then allow for coping skill development programs to be created to target specific outcomes to a certain type of coping.

Therefore, to address these gaps the current research questions guiding this study are as follows:

1. What are the daily stressors for YCs?
2. What are the coping strategies most frequently used by YCs?
3. Do coping strategies (i.e., problem-focused disengagement, problem-focused engagement, emotion-focused disengagement, and emotion-focused engagement) moderate the relation between YC stressors and negative psychosocial outcomes such as depression, anxiety, loneliness, and self-esteem?

For the first question, it was hypothesized that the key stressors would be concentrated on the perceived role stress category of the scale. Research by Sexton et al. (2018) suggests that

frequent stressors of YCs link with lack of time, such as “not enough sleep” or “having too much homework.” This justifies the hypothesis of perceived role stress being the most frequently selected stressors.

For the second question, it was hypothesized that a mix of emotion-focused disengagement and emotion-focused engagement dominating the results. Previous research suggests that YCs use more disengagement and emotion-focused coping strategies, which justified this hypothesis (Sexton et al., 2018). For the third question, it was hypothesized that problem-focused engagement coping would be a moderator between stress and anxiety, and stress and loneliness. It was also hypothesized that emotion-focused engagement coping would be a moderator between stress and depression and between stress and self-esteem. These hypotheses were developed in line with previous results in which different forms of coping showed stronger relations depending on the psychosocial outcome (Chen et al., 2015; Evans et al., 2015; Garcia-Alberca et al., 2012; Pakenham et al., 2007; Sexton et al., 2018).

CHAPTER THREE: METHODOLOGY

Participants

This study encompassed 58 participants ($N = 58$) between the ages of 10 to 18 recruited in the Niagara, Hamilton, Halton, Haldimand-Norfolk, and Toronto regions. Power analysis was run previous to recruitment to determine the number of participants needed for statistical significance. GPower determined a minimum of 55 YCs were needed to ensure sufficient statistical power. Participants were recruited through the assistance of local community agencies and through advertisement through posters and social media. However, as only a limited number of agencies agreed to help in this process, the recruitment was opened up to specific YC support programs as a targeted sample.

Within the sample, 31 participants were female (55.4%) and 25 were male (41.9%); two participants (3.4%) did not indicate sex. The age range was from 10 to 18+ years of age with a mean age of 13 years. The mode for age of the participants was 10 years old. For male participants $M_{\text{male}} = 5.96$ (14 years), $SD = 2.37$ and female participants were significantly younger $M_{\text{female}} = 4.19$ (12 years), $SD = 2.06$. All of the participants were identified as YCs by agencies or through the screening process in the beginning of the questionnaire. The screening process asked questions in the demographic section of the questionnaire (see Appendix A) to help explore if they are a YC. Also, the recruitment poster characterized a YC as a young person between the ages of 10 to 18 who takes on extra responsibilities to help out a family member. No potential participants were deemed inappropriate for this study. The majority of the participants (89.5%) completed the in-person questionnaire and the remaining participants (6.9%) completed the questionnaire online. Ninety-three percent of the participants attended a local YC support agency, while the remaining 7% did not have access to these supports. On average, the

participants who were part of the local YC support program attended for approximately 3 years ($M = 3.91$, $SD = 2.27$, range less to a year to 9 years).

Procedure

Upon clearance by the Brock University Research Ethics Board (File #16-216; see Appendix B), recruitment began through contacting community agencies, posters, and social media outlets. Recruitment focused on finding YCs between the ages of 10-18. There were two version of the questionnaire: one that was to be completed online through Qualtrics software and one version that was to be done in person. Therefore, there were two different procedures depending on if the participant chose to complete the questionnaire online or in person.

In-Person Questionnaire Procedure

Participants who completed the in-person questionnaire were selected based on their age from a local YC support agency that supports over 300 YCs in the geographic region it serves. Program staff selected members of the program if their ages were between 10 to 18 and were asked if they wanted to learn more about a Brock University research study about young caregivers. Participants who wanted to learn more about the research then went into a secure location and were informed about the consent needed to complete the questionnaire. Participants were then given a consent form (see Appendix C) and were asked to read the consent form and then responded whether they wanted to take part in the research their response, by circling yes or no. Those who selected “yes” then had to write their name, age, and date on the back of the consent form. Those who selected “no” could then return back to their regular program. Participants who wished to complete the research were then given the questionnaire. If they had questions, research assistants would help clarify. After participants had completed their questionnaire, they were given a contact information sheet which asked if they wanted to receive a summary of the results. If they chose to receive it, they were asked to fill in their contact

information. Each participant also received a support services sheet (see Appendix D) with contact numbers if they felt down or upset after completing the questionnaire. The questionnaire took participants approximately 30 to 45 minutes to complete.

Online Questionnaire Procedure

Participants who completed the online questionnaire could have found out about the study through posters, newspaper, social media, or thought the local YC agency. After participants heard about the research study they would start the process by emailing the research team and expressing interest in the study. After the participant contacted the research team, a consent form, which outlined the study, was sent through email. The participants were asked to fill in their age and the date on the consent form. This was done to ensure that the participant was in the required age range (12 to 18 years of age). After participants had returned the consent form, an anonymous link populated by Qualtrics software was sent to them. After participants had completed the questionnaire, they were asked if they wanted a summary of the results. If they selected “yes” then they were asked for their contact information. If they selected “no” it automatically went to the end of the survey. After this section was complete, the final page of the questionnaire included the support services sheet (see Appendix D) that had contact numbers if they felt down or upset after completing the questionnaire. The questionnaire took participants approximately 15 to 35 minutes to complete.

Measures

Stress

Participants completed the 19-item Young Carers Perceived Stress Scale (YCPSS) (Early et al., 2006) that measured perceived stress of YC within five different factors. This scale was adapted for the Canadian context; therefore three items were removed. The subscales include: 1. Perceived Role Stress (e.g., “It bothers me that I can’t have a life of my own”); 2. School Impact

(e.g., “It bothers me what other kids will say if I take time off school”); 3. Social Impact (e.g., “Getting teased about being a carer is a problem for me”); 4. Family Impact (e.g., It bothers me that my family argues about caring”); and 5. Social Recognition of Role (e.g., “It bothers me that people never say they are pleased with my caring”). The items were rated on a 5-point Likert scale (1 = *I disagree a lot* to 5 = *I agree a lot*). This scale was chosen to examine what stressors are prevalent within the caregiving role. Pakenham et al. (2006) found that using generic stress measures indicated fewer differences between YCs and non-YCs and therefore encouraged the use of measures specific to the YC population to understand the unique qualities and impacts of the role. A composite for overall stress was created and the scale reliability was $\alpha = .76$. Higher scores represent higher levels of stress (see Appendix E).

Coping

The Coping Strategies Inventory (Tobin et al., 1982) is a 72-item self-report questionnaire. This scale was adapted and shortened for the purposes of this study and included 24 items. The creation of this scale was based on the Ways of Coping questionnaire (Folkman & Lazarus, 1981), but the scale was also developed using research based on each subscale to create more questions. The participants first think of a stressful situation and then answer questions surrounding what strategies they would use on a 5-point Likert scale (0 = *Not at all* to 4 = *Very much*). The stressor that is chosen by the participant could be related to their YC role or could be a normative stressor. There are eight subscales which include problem solving, cognitive restructuring, social support, express emotions, problem avoidance, wishful thinking, social withdrawal, and self-criticism. There were three items in each subscale chosen for 24 total scale items.

The secondary subscales include problem-focused engagement (problem solving and cognitive restructuring; $\alpha = .54$), emotion-focused engagement (social support and express

emotions, $\alpha = .81$), problem-focused disengagement (problem avoidance and wishful thinking, $\alpha = .71$), and emotion-focused disengagement (social withdrawal and self-criticism, $\alpha = .69$).

Reliability analysis was conducted on each subscale to determine if the items worked together.

Due to low reliability in the problem-focused disengagement scale, one item was removed and then satisfied the $\alpha > .60$. In addition, the problem-focused engagement scale was removed due to low reliability. The low reliability could be related to the scale originally having nine items in each subscale, which was then condensed to three items per subscale to adapt for the purposes of this study. It also may be due to the questions that were selected and the developmental level of the participants in the comprehension of each item's meaning. Higher scores represent an increase in the use of each of the coping strategies (see Appendix F).

Self-Esteem

The Rosenberg Self-Esteem Scale (Rosenberg, 1965) is a 10-item scale that was adapted for the purposes of this study and is a 5-point Likert scale (1 = *Strongly agree* to 4 = *Strongly disagree*). An example of a question would be "I feel that I have a number of good qualities" or "At times I think I am no good at all." A composite measure for overall self-esteem was created with a reliability of $\alpha = .89$. Higher scores represent lower self-esteem (see Appendix G).

Depressive Symptoms

The CES-DC (Weissman, Orvaschel, Padian, 1980) is a child-friendly 20-item scale on depression that asks the participant to report the frequency of 20 feelings/behaviours during the past week and is a 4-point Likert scale (0 = *Not at all* to 3 = *A lot*). Questions corresponded to depressed mood, loss of appetite, and other factors related to depression. An example of a scale item is "I was bothered by things that usually don't bother me." A composite measure for overall

depressive symptoms was created with a reliability of $\alpha = .75$. Higher scores represent higher levels of depressive symptoms (see Appendix H).

Anxiety

An adapted version of the original 44-item version of The Spence Children's Anxiety Scale (Spence, 1998) was used to measure the severity of specific anxiety symptoms related to generalized anxiety and separation anxiety. It is measured on a 4-point frequency scale (ranging from 0 = *Never* to 3 = *Always*). Only the two subscales of generalized anxiety and separation anxiety were used as measures for this study, although there are six subscales of anxiety in this measure. A couple examples of a scale items are "I worry about being away from my parents" and "When I have a problem, my heart beats really fast." A composite was created for overall anxiety with a reliability of $\alpha = .86$. Higher scores represent higher levels of anxiety (see Appendix I).

Loneliness

An adapted 16-item version of the Louvain Loneliness Scale for Children and Adolescents (Marcoen, Goossens, & Caes, 1987) was used to measure aversion to loneliness and affinity to loneliness. There are typically four subscales within this measure but aversion to loneliness and affinity to loneliness were chosen as representative within this study's context. This 4-point Likert scale has eight items, ranging from 1 = *Almost never or never* to 4 = *Almost always or always*. An example of a scale item is "I am unhappy when I have to do things on my own." A composite was created for overall aversion to loneliness ($\alpha = .84$) and for overall affinity to loneliness ($\alpha = .76$). Higher scores represent higher levels of loneliness (see Appendix J).

Data Analysis

The data were analyzed using IBM SPSS statistics 24 software. The data were cleaned and assumptions were checked. There were three main questions to be explored. The data were

screened for missing data and there was 5.2% missing data. Therefore, multiple imputation was utilized with five iterations to impute the missing data. There was one participant removed due to incomplete data. The imputed data were consistent with the original data set findings therefore the original data set findings were reported and listwise deletion was used. Outliers were checked with all values found to be within normal range. Normality was assessed using skew and kurtosis values with all values not in a problematic range.

After the data were cleaned, descriptives on all demographic variables were run to see the contextual variables associated with the sample. For analysis, reliability was checked for each of the overall variables needed for further analysis. All overall variables with a reliability of $\alpha = .60$ or higher were created into a composite. Composites were made for overall stress levels, self-esteem, depression, anxiety, aversion to loneliness, and infinity to loneliness. Composites were also created for the coping variable but were separated into four secondary subscales of problem-focused disengagement, problem-focused engagement, emotion-focused disengagement, and emotion-focused engagement. However, problem-focused engagement was removed from analysis due to low reliability ($\alpha = .54$) of the items.

The first question was explored through frequencies to determine the most frequently reported caregiving stressors. The second question was also explored through frequencies to determine the most frequently reported coping strategies used.

The third question was explored through correlational analyses on the overall stressors, each of the overall psychosocial outcomes, and each of the three coping strategy composites. This was done to determine if there were associations between all the variables. For all analyses, a significance level of $p < .05$ was used. To answer the third question the PROCESS plugin for SPSS (Hayes, 2012) was used to determine if any of the three coping strategies categories

(problem-focused disengagement, emotion-focused disengagement, and emotion-focused engagement) were moderators for the relations between overall stress and each of the psychosocial outcomes (depressive symptoms, anxiety, self-esteem, aversion to loneliness, and affinity to loneliness).

CHAPTER FOUR: RESULTS

Descriptive Statistics—Young Carer Context

YCs provide care for a family member in their family due to a physical disability, chronic illness, mental illness, addiction, or language barrier (Aldridge & Becker, 1993; Charles et al., 2008; Stamatopoulos, 2015). Within this sample there were a majority of YCs caring for their brother (32.9%), their mother (22.4%), and their sister (17.1%). There were minimal YCs caring for fathers and extended family members (see Figure 5). The reason for caring was dominated by Autism (31.7%; see Figure 6). The average years providing care was 7 years ($M = 7.15$, $SD = 3.79$), and the mean age of starting to provide care was the age of 6 ($M = 5.73$, $SD = 2.51$). There were no significant differences found between male and female participants on years providing care, $t(43) = 1.92$, $p = .06$ or age of starting to provide care, $t(42) = .65$, $p = .51$.

The participants on average spend 3-4 hours per day providing care ($M = 2.93$, $SD = 1.56$), including 62.5% spending between 1-4 hours per day providing care. However, the mode for hours providing care was 1-2 hours per day. There were no significant differences found between male and female participants on time spent providing care for their family member, $t(52) = .08$, $p = .94$. The participants reported they usually do household tasks at home, whereas participants reported they sometimes emotionally supported their family members. Participants reported occasionally doing meal preparation for their family. The least reported responsibilities were managing the house, translation, personal and medical care (see Table 1; see Figure 4). There were no significant differences on responsibilities between males and females. There were significant differences on age when comparing ages 10-13 and 14 -18, on household tasks, $t(56) = -.2.32$, $p = .024$, helping siblings $t(56) = -2.05$, $p = .045$, and medical care $t(34.42) = -2.15$, $p = .024$. This was shown by a higher mean value for older participants suggesting a higher level of

responsibility. There were 42 (76.4%) YCs who selected ‘yes’ that they thought they were a young caregiver. However, that leaves 16 (23.6%) who either selected “no,” “maybe,” “don’t know,” or were missing.

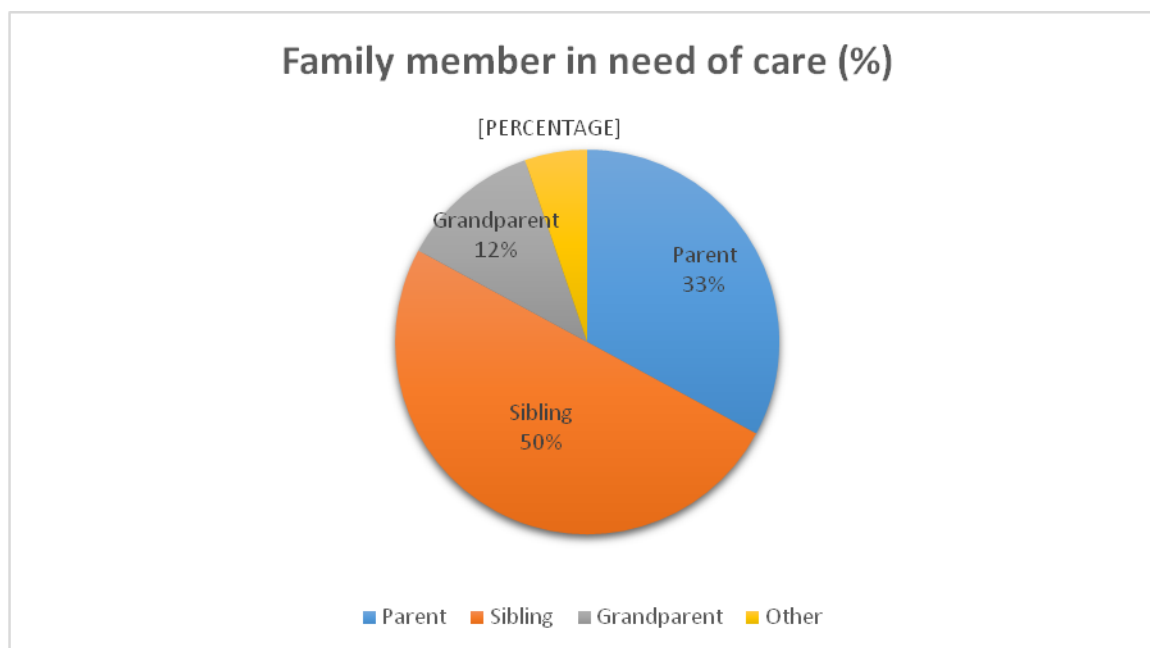


Figure 4. Family member in need of care (%).

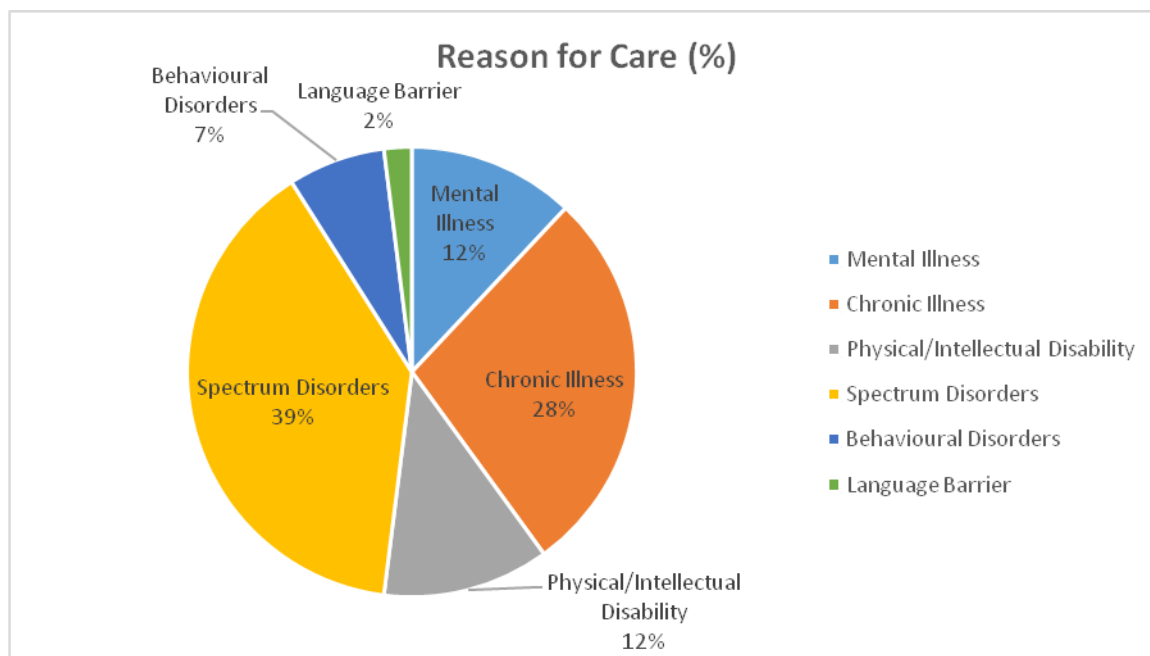


Figure 5. Reason for care (%).

Table 1

Young Carer Responsibilities

		Young carers (<i>n</i> = 58)					
		Does not apply	Rarely	Occasionally	Sometimes	Usually	Most of the time
Responsibilities							
	Household tasks	2 (3.4%)	3 (5.2%)	3 (5.2%)	9 (15.5%)	17 (29.3%)	24 (41.4%)
	Meal preparation	4 (7%)	12 (21.1%)	11 (19.3%)	19 (33.3%)	4 (7%)	7 (12.3%)
	Helping siblings	12 (20.7%)	15 (25.9%)	6 (10.3%)	6 (10.3%)	10 (17.2%)	9 (15.5%)
	Personal care	24 (42.9%)	14 (25%)	8 (14.3%)	5 (8.9%)	4 (7.1%)	1 (1.8%)
	Medical care	25 (44.6%)	12 (21.4%)	7 (12.5%)	9 (16.1%)	1 (1.8%)	2 (3.6%)
	Managing the house	36 (34.3%)	16 (28.6%)	1 (1.8%)	3 (5.4%)	0 (0%)	0 (0%)
	Translation	30 (61.2%)	10 (20.4%)	2 (4.1%)	2 (4.1%)	2 (4.1%)	3 (6.1%)
	Emotional support	4 (8%)	9 (18%)	4 (8%)	11 (22%)	9 (18%)	13 (26%)
	Other	14 (45.2%)	2 (6.5%)	0 (0%)	2 (6.5%)	7 (22.6%)	6 (19.4%)
Average	(Responsibilities)	N =	M =	SD =			
	Household tasks	(<i>n</i> = 58)	<i>M</i> = 3.86	<i>SD</i> = 1.34			
	Meal preparation	(<i>n</i> = 57)	<i>M</i> = 2.49	<i>SD</i> = 1.42			
	Helping siblings	(<i>n</i> = 58)	<i>M</i> = 2.24	<i>SD</i> = 1.81			
	Personal care	(<i>n</i> = 56)	<i>M</i> = 1.18	<i>SD</i> = 1.36			
	Medical care	(<i>n</i> = 56)	<i>M</i> = 1.19	<i>SD</i> = 1.39			
	Managing the house	(<i>n</i> = 56)	<i>M</i> = .48	<i>SD</i> = .79			
	Translation	(<i>n</i> = 49)	<i>M</i> = .88	<i>SD</i> = 1.48			
	Emotional support	(<i>n</i> = 50)	<i>M</i> = 3.02	<i>SD</i> = 1.67			
	Other	(<i>n</i> = 31)	<i>M</i> = 2.13	<i>SD</i> = 2.17			

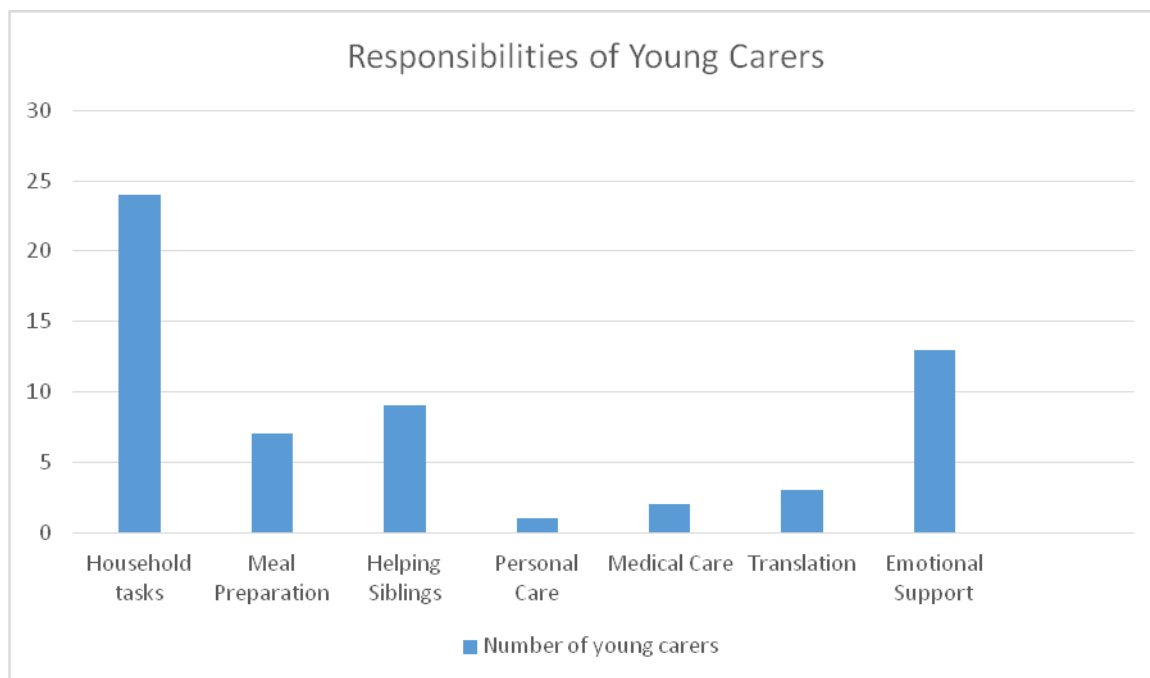


Figure 6. Responsibilities of young carers (%).

Frequency of YC Stressors

To answer the first research question, frequencies were conducted on YC stressors. The top five most frequently reported YC stressors were: 1. It bothers me that people never say that they are pleased with my caring (51.7%); 2. I think I work hard at caring but nothing seems to change (36.2%); 3. It bothers me what teachers will say if I fall behind in school (22.4%); 4. It bothers me that other people don't understand what I do to help my family (20.7%); and 5. I feel left out in my family (17.2%). The three least-reported YC stressors were: 1. I am bothered I have missed too much school (3.5%); 2. It bothers me that I can't take part in clubs or activities after school (5.2%); and 3. Getting teased about being a carer is a problem for me (5.4%). (See Table 2.)

Table 2

Frequency of Young Carer Stressors

Stressors	M = SD =	Young carers (n = 58)				
		I disagree a lot	I disagree a little	I neither agree nor disagree	I agree a little	I agree a lot
It bothers me that caring takes over everything in my life	M = 2.83 SD = 1.33	24.1	13.8	27.6	24.1	10.3
It bothers me that I can't have a life of my own	M = 2.68 SD = 1.51	33.9	16.1	14.3	19.6	16.1
I feel there is no break from caring	M = 2.58 SD = 1.41	33.3	14	28.1	10.5	14
It's hard to get a rest from caring	M = 2.52 SD = 1.34	29.3	25.9	19	15.5	10.3
I feel tired because of the caring I do	M = 2.56 SD = 1.34	32.7	16.4	18.2	27.3	5.5
It bothers me what other kids will say if I take time off school	M = 2.29 SD = 1.46	48.3	8.6	20.7	10.3	12.1
I am bothered that I have missed too much school	M = 1.74 SD = 1.16	64.9	10.5	14	7	3.5
I worry that if I wasn't caring I wouldn't know what to do with myself	M = 2.64 SD = 1.36	27.6	20.7	24.1	15.5	12.1
It bothers me what teachers will say if I fall behind in school	M = 2.88 SD = 1.60	34.5	6.9	17.2	19	22.4
Getting teased about being a carer is a problem for me	M = 2.00 SD = 1.25	53.6	10.7	23.2	7.1	5.4
It bothers me that I can't take part in clubs or activities after school	M = 2.33 SD = 1.37	44.8	8.6	20.7	20.7	5.2
Feeling different from others kids is a problem for me	M = 2.27 SD = 1.47	48.2	12.5	16.1	10.7	12.5

It bothers me that my family argues about caring	$M = 2.44$ $SD = 1.39$	40.4	10.5	21.1	21.1	7
I feel left out in my family	$M = 2.57$ $SD = 1.60$	43.1	10.3	10.3	19	17.2
I don't know where I belong in my family	$M = 2.28$ $SD = 1.61$	56.9	3.4	10.3	13.8	15.5
It bothers me that people never say they are pleased with my caring	$M = 3.84$ $SD = 1.37$	8.6	8.6	24.1	6.9	51.7
It bothers me that other people don't understand what I do to help my family	$M = 2.88$ $SD = 1.45$	20.7	27.6	15.5	15.5	20.7
I think I work hard at caring but nothing seems to change	$M = 3.41$ $SD = 1.49$	15.5	15.5	17.2	15.5	36.2
The people that I know understand about my caring	$M = 3.50$ $SD = 1.20$	8.6	10.3	25.9	32.8	22.4

Frequency of Coping Strategies

To answer the second research question, frequencies were conducted on coping strategies. The top five most frequently reports coping strategies were: 1. I wished that the situation would go away or somehow be over with (41.1%); 2. I spent some time by myself (32.1%); 3. I did not let others know how I was feeling (30.9%); 4. I spent some time with my friends (25.9%); and 5. I didn't talk to other people about the problem (21.4%). The three least reported coping strategies were: 1. I reorganized the way I looked at the situation, so things didn't look so bad (3.6%); 2. I avoided thinking or doing anything about the situation (5.5%); and 3. I hope the problem would take care of itself (7.1%). (See Table 3.)

Table 3

Frequency of Young Carer Coping Strategies

Coping strategies (%)	Young carers (<i>n</i> = 58)					
	<i>M</i> = <i>SD</i> =	Not at all	A little	Somewhat	Much	Very much
I just concentrated on what I had to do next; the next step	<i>M</i> = 1.73 <i>SD</i> = 1.21	19.6	21.4	33.9	16.1	8.9
I hoped the problem would take care of itself	<i>M</i> = 1.34 <i>SD</i> = 1.25	32.1	28.6	19.6	12.5	7.1
I went along as if nothing were happening	<i>M</i> = 1.37 <i>SD</i> = 1.38	38.6	19.3	19.3	12.3	10.5
I realized that I brought the problem on myself	<i>M</i> = 1.16 <i>SD</i> = 1.15	36.8	26.3	26.3	5.3	5.3
I told myself things that helped me feel better	<i>M</i> = 1.30 <i>SD</i> = 1.37	42.9	14.3	21.4	12.5	8.9
I talked to someone about how I was feeling	<i>M</i> = 1.39 <i>SD</i> = 1.36	30.4	33.9	16.1	5.4	14.3
I blamed myself	<i>M</i> = 1.39 <i>SD</i> = 1.53	45.6	12.3	15.8	10.5	15.8
I made a plan of action and followed it	<i>M</i> = 1.40 <i>SD</i> = 1.27	29.8	28.1	22.8	10.5	8.8
I wished that the situation would go away or somehow be over with	<i>M</i> = 2.45 <i>SD</i> = 1.59	19.6	12.5	12.5	14.3	41.1
I let my feelings out somehow	<i>M</i> = 1.49 <i>SD</i> = 1.15	20	34.5	30.9	5.5	9.1
I didn't talk to other people about the problem	<i>M</i> = 1.78 <i>SD</i> = 1.51	26.8	25	14.3	12.5	21.4
I let my emotions out	<i>M</i> = 1.25 <i>SD</i> = 1.48	48.2	14.3	16.1	7.1	14.3
I spent some time by myself	<i>M</i> = 2.41 <i>SD</i> = 1.45	16.1	10.7	21.4	19.6	32.1
I stepped back from the situation and put things into perspective	<i>M</i> = 1.69 <i>SD</i> = 1.36	29.1	12.7	29.1	18.2	10.9
My feeling were overwhelming and they just exploded	<i>M</i> = 1.62 <i>SD</i> = 1.55	36.4	14.5	20	9.1	20

I asked a friend or relative I respect for advice	$M = 1.40$ $SD = 1.44$	41.8	12.7	20	14.5	10.9
I made light of the situation and refused to get too serious about it	$M = 1.28$ $SD = 1.26$	34	30.2	17	11.3	7.5
I hoped that if I waited long enough, things would turn out OK.	$M = 1.56$ $SD = 1.41$	33.3	18.5	18.5	18.5	11.1
I kicked myself for letting this happen	$M = 1.09$ $SD = 1.49$	56.4	12.7	10.9	5.5	14.5
I worked on solving the problems in the situation	$M = 1.84$ $SD = 1.26$	16.4	25.5	29.1	16.4	12.7
I reorganized the way I looked at the situation, so things didn't look so bad	$M = 1.33$ $SD = 1.11$	29.1	25.5	32.7	9.1	3.6
I spent some time with my friends	$M = 2.18$ $SD = 1.45$	15.5	19	19	15.5	25.9
I avoided thinking or doing anything about the situation	$M = 1.24$ $SD = 1.29$	41.8	18.2	20	14.5	5.5
I did not let others know how I was feeling	$M = 2.00$ $SD = 1.58$	21.8	25.5	14.5	7.3	30.9

Correlation Analyses Results

To address the third research question, Pearson correlations were used to first examine the correlations between each of the overall variables of YC stressors, coping strategies, and psychosocial outcomes. The five psychosocial outcomes that were explored were depressive symptoms, anxiety, self-esteem, aversion to loneliness, and affinity to loneliness. The three different coping strategy composites that were used for the correlation analyses were emotion-focused engagement, emotion-focused disengagement, and problem-focused disengagement. The correlations ranged from .11 to .56 with small to large effect size (see Table 4). Four relations were found to be not significantly correlated including problem-focused disengagement and aversion to loneliness ($p = .096$), emotion-focused disengagement and aversion to loneliness ($p = .216$), emotion-focused engagement and self-esteem ($p = .814$), and emotion-focused engagement and affinity to loneliness ($p = .064$; see Table 4).

Table 4

Correlations Between Overall YC Stress, Coping, and Psychosocial Outcomes

Variable	1	2	3	4	5	6	7	8	9
1. Overall YC stress	1	.446**	.550**	.382**	.344**	.467**	.458**	.508**	.391**
2. Overall depressive symptoms		1	.425**	.483**	.393**	.559**	.354**	.436**	.435**
3. Overall self-esteem			1	.362**	.115	.465**	.302*	.498**	.032
4. Overall anxiety				1	.515**	.360**	.383**	.388**	.577**
5. Overall aversion to loneliness					1	.076	.225	.216	.493**
6. Overall affinity to loneliness						1	.359**	.536**	.252
7. Problem-focused disengagement coping							1	.557**	.411**
8. Emotion-focused disengagement coping								1	.161
9. Emotion-focused engagement coping									1

* *p* value significant at $p < .05$; ***p* value significant at $p < .01$

Moderation Models Results

The second part, in order to address the third research question, was a moderation model with 15 different models. This analysis was conducted using the Process plug in on SPSS (Hayes, 2012). The three different categories of coping strategies (i.e., problem-focused disengagement, emotion-focused disengagement, and emotion-focused engagement) were examined as a moderator of the relation between overall stress and different psychosocial outcomes (i.e., depressive symptoms, anxiety, self-esteem, aversion to loneliness, and affinity to loneliness). The results showed that none of the three types of coping strategies were moderators for depressive symptoms, anxiety, self-esteem, aversion to loneliness, or affinity to loneliness. The Beta values ranges from $\beta = -.018$ to $\beta = .177$. There were no significant differences found for these models (see Table 5). Follow up analyses were run to examine possible explanations; the results showed there were significant correlations between breadth of coping and four of the psychosocial outcomes (see Table 6).

Table 5

Moderation Model Results (Independent Variable = Overall YC Stress)

Model	Outcome	Moderator	β	p	95% CI
1	Depressive symptoms	Problem-focused disengagement	.058	.631	-.182, .297
2	Depressive symptoms	Emotion-focused disengagement	.022	.848	-.212, .257
3	Depressive symptoms	Emotion-focused disengagement	.028	.731	-.136, .192
4	Self-esteem	Problem-focused disengagement	.109	.480	-.200, .419
5	Self-esteem	Emotion-focused disengagement	-.065	.666	-.363, .234
6	Self-esteem	Emotion-focused disengagement	.044	.688	-.173, .260
7	Anxiety	Problem-focused disengagement	-.018	.909	-.328, .292
8	Anxiety	Emotion-focused disengagement	-.066	.672	-.379, .246
9	Anxiety	Emotion-focused disengagement	.059	.553	-.139, .257
10	Aversion to loneliness	Problem-focused disengagement	.177	.324	-.179, .532
11	Aversion to loneliness	Emotion-focused disengagement	.177	.351	-.201, .556
12	Aversion to loneliness	Emotion-focused disengagement	.129	.263	-.100, .359
13	Affinity to loneliness	Problem-focused disengagement	-.083	.589	-.389, .223
14	Affinity to loneliness	Emotion-focused disengagement	-.198	.191	-.497, .102
15	Affinity to loneliness	Emotion-focused disengagement	-.102	.327	-.309, .105

Table 6

Correlations Between Breadth of Coping and Psychosocial Outcomes

Variable	1	2	3	4	5	6
1. Breadth of coping	1	.304*	.169	.428**	.372**	.349**
2. Overall depressive symptoms		1	.425**	.483**	.393**	.559**
3. Overall self-esteem			1	.362**	.115	.465**
4. Overall anxiety				1	.515**	.360**
5. Overall aversion to loneliness					1	.076
6. Overall affinity to loneliness						1

* *p* value significant at $p < .05$; ** *p* value significant at $p < .01$

CHAPTER FIVE: DISCUSSION

Research on stress and coping within the YC population is very limited. The current research may help to build a better understanding of YCs' stress and coping strategies used by YCs in their daily lives. This is critical information as the YC population is often hidden from society as many are unaware of YCs and YCs often choose not to share about their caregiving role with others (Bolas et al., 2007; Smyth et al., 2011).

Descriptive Statistics—Young Carer Context

This sample was diverse in the types of stressors and coping strategies used yet highlighted similarities among YCs. This sample is consistent with previous research in other countries regarding age, length of caregiving, and whom they provide care (Nagl-Cupal et al., 2014; Shifren & Kachorek, 2003; Warren, 2007). Given the early start to caregiving (average age of 6), this suggests that the caregiving role has made up the majority of their life to date and the reason for care is typically within the nuclear family (e.g., sibling or parent). A finding unique to this study is that this sample highlighted that for many YCs caregiving responsibilities were for multiple family members, thereby potentially increasing stress levels.

As Lakman and Chalmers (2018) noted, the amount of time spent caring can equal to a part-time or even full-time job. Present findings support the great number of hours YCs spend on caring for their family members. These results are consistent with previous studies suggesting that this amount of time caring is consistent for YCs across different samples (Banks et al, 2002; Lakman & Chalmers, 2018; Moore et al., 2009; Nagl-Cupal et al., 2014). In a YC's 24-hour day, this may equate to: 10 hours sleeping, 2 hours eating/getting dressed, 7 hours school/transportation, and 4 hours caring. This leaves 1 hour unaccounted for where homework, connecting with friends, and/or relaxing should also happen in a YC's day. Due to the high level

of caring responsibilities, this could lead to further isolation and possible negative psychosocial outcomes such as depressive symptoms, anxiety, loneliness, or low self-esteem (Charles et al., 2008; Collins & Bayless, 2013; Frank et al., 1999; Lakman & Chalmers, 2018; Sahoo & Suar, 2010).

The results show that household tasks, emotional support, and meal preparation were the tasks YCs did the most often. Although no sex differences were found in the types of responsibilities of this sample, other researchers found sex differences along more typically gendered lines as females did more household tasks (e.g., cooking and cleaning), whereas males did more physical caring (lifting and assisting with mobility; Aronson, 1992; Belansky & Boggiano, 1994; Dwyer & Seccomb, 1991; Hequembourg & Brallier, 2005). Consistent with other research (McDonald et al., 2010), age differences were found in some responsibilities that suggest as YCs get older they take on more responsibilities. McDonald et al. (2010) found that parents felt by the age of 10 to 12 their children were able to take on more responsibility and had increased maturity sufficiently to handle the increased demands.

Caregiving frequently occurs on a continuum (Becker, 2007). In the current study, personal care, medical care, managing the house, and translation had a low mean value. Further, the most frequently selected time spent caring per day was 1-2 hours. This suggests that carers within this sample are located in the lower to middle range of caregiving and may experience lower levels of stress than those who have higher levels of caregiving and responsibility (Becker, 2007). Therefore, results from this study may not be applicable to YCs along the entire continuum of care.

The vast majority of this sample (93%) has had some exposure to a YC support program. The fact that they are part of a support program suggests parents identified their need for support

and made time to ensure their YC could attend program and develop skills to assist with caregiving. The average length of time that participants were part of the program was for 3 years; this creates a limitation due to the participants being identified as a YC already and that they have access to support services through this program.

Research has long supported that YCs are hidden from societal awareness (Bolas et al., 2007; Smyth et al. 2011). It was interesting to note that in this study almost a quarter (23.7%) of the sample did not identify as a YC. Given that the majority of the participants were recruited through a YC support agency, this raises questions of self-identification. It may be that YCs see their responsibilities as just “helping out” at home and not actually “caring” for a family member (Smyth et al., 2011). This also would make sense due to the average age of beginning care was 6 years old and would suggest it was their norm and just the way things are in their family for as long as they can remember.

YCs may not want to take on the label of a “young carer” because of the stigma associated with the label or the stigma of the reason they are caring for their relative (Smyth et al., 2011). There is also fear of social service intervention if others find out about their caregiving role or extra responsibilities. This can translate into the YC remaining hidden and not sharing their role with others (Aldridge & Becker, 1993; Smyth et al., 2011). In addition, YCs in previous research have said it is easier to keep their role a secret rather than expecting others to accept and understand their family role (Bolas et al., 2007). This can lead to the YC remaining hidden and not seeking social support due to possible consequences such as peer rejection or intervention by social services. While no sex differences were found with respect to YC self-identification, Smyth et al. (2011) suggest that gender may have a role in whether a child or

youth identifies as a YC; males may be less likely to share about their caregiving role due to societal norms regarding masculinity.

Frequency of YC Stressors

The results showed a clear trend that social recognition was a prominent stressor for YCs. Three of the five top stressors were a desire for social recognition. This shows a wish for validation and recognition of their multiple roles. For example, YCs may feel others in their family do not notice their extra responsibilities. The family would appear to be the social circle that would allow for the most effective support, but research by Aldridge and Becker (1993) suggests that the family may not offer the support or validation that the YC needs.

Results suggests that within the family, YCs experience stress if their contributions do not appear to make a positive difference for the family. When a family member has a diagnosis that is chronic as opposed to intermittent, there may be no “good” days or “bad” days but just the same level of care each day with little change. When no improvement in the family member is seen, it may seem to the YC that what they are doing is not making a difference to the family unit. Not feeling included within the family was also a key stressor. Aldridge and Becker (1993) have also reported this type of stressor as YCs found that the family was not a place where they felt supported but often the majority of the caring responsibilities fell on the YC, even when there were other family members who were able to help. Compounded by invalidation of their role within their family, this could lead to high levels of stress. Recognition of the YC role outside of the family was one of the most frequently identified stressors. Research by Chalmers and Lucyk (2012) further justifies this response, as it was common for YCs to report feeling unsupported inside and outside of their nuclear family. All of these stressors suggest that YCs want others to understand their extra responsibilities, however, previous research suggests that YCs are worried about judgment and lack of understanding of their role (Aldridge & Becker,

1993; Bolas et al., 2007; Smyth et al., 2011; Thomas et al., 2003). Specific to the school context, research revealed that YCs want general awareness about the role of a YC, but do not want others within the school to identify them as a YC (Mansell, 2016). These findings highlight how the conflict between the desire for recognition and anonymity create heightened stress. A study by Bolas et al. (2007) revealed that YCs who experience validation and felt useful, capable, and appreciated had higher levels of self-esteem. These results suggest that a lack of validation from inside and outside of the family may decrease self-esteem and/or self-efficacy. The lack of self-efficacy can lead to increased depression and anxiety symptoms (O'Dell et al., 2010; Sahoo & Suar, 2010; Smyth et al., 2011).

School context, specifically related to teacher perception, was another identified stressor. Lakman, Chalmers, and Sexton (2017) found that YCs typically receive high grades and it was important to YCs to do well in school and get good grades. This suggests that a teacher thinking they may be behind in school would cause stress, as doing well in school is deemed as important. Previous research has supported that YCs do not discuss their caregiving role with teachers because they feel teachers will not understand their responsibilities (Aldridge & Becker, 1993; Bolas et al., 2007; Thomas et al., 2003), with the lack of understanding leading to assumptions that YCs were making excuses or telling lies for not having their homework done (Bolas et al., 2007). Therefore, YCs may be concerned about feeling forced to share their caregiving role if their teacher thinks they are falling behind in school. However, YCs expressed that they would rather keep their role a secret rather than expect others to understand their responsibilities (Aldridge & Becker, 1993; Bolas et al., 2007; Thomas et al., 2003).

It was hypothesized that the top stressors would be related to perceived role stress; however, the results revealed a different outcome. Three of the five top stressors were within the social recognition of the role category, therefore the hypothesis was not supported. Given that the

majority of participants were in the middle of the continuum of care, YCs may not have been as restricted as other YCs by their role. The fact that 93% of participants attended a YC support program suggests that social opportunities for these YCs may not be as restricted as YCs at the “very heavy” end of the continuum (Becker, 2007).

Frequency of Coping Strategies

Results revealed that YCs most frequently used disengagement coping strategies (e.g., wishful thinking or social withdrawal) and less frequently used engagement coping strategies (e.g., problem solving or seeking social support). It is important to note that when participants selected how often they use a specific coping strategy, it may not have been to address a stressor related to the YC role but could be a normative stressor. These results are consistent with previous research suggesting the frequent use of avoidance type coping strategies by YCs (Sexton et al., 2018). Use of disengagement coping strategies may be related to the types of stressors which are often chronic. YCs may feel that the only way to escape the stressor is to pretend it is not there. Research by Bolas et al. (2007) revealed that YCs do not want to disclose distress because this creates negative feelings towards themselves such as guilt and depressive symptoms (Aldridge & Becker, 1993; Banks et al., 2002; Frank et al., 1999). YCs also seem to turn their stress inward and withdraw from others which suggests a lack of sharing and openness both inside and outside of their family (Aldridge & Becker, 1993; Bolas et al., 2007; Chalmers & Lucyk, 2012). When YCs turn their stress inward, this may increase their levels of stress and limit the support available to them.

One of the coping strategies cited—“I spent time by myself”—may be interpreted in one of two ways. Within this scale, this item was considered a social withdrawal strategy, however, it may also be a prosocial strategy. Previous research has focused on the withdrawal hypothesis

with YCs feeling the need to withdraw from those around them, in order to reduce the likelihood of negative attitudes about their caregiving role (Bolas et al., 2007). In contrast, spending time by oneself could be positive by taking a break and revitalizing before continuing with one's responsibilities. Further analyses discovered that there was a significant positive correlation between this coping strategy and overall affinity to being alone. These YCs like to spend time alone, thus providing support that this coping strategy could be prosocial. These results should be interpreted with caution, as there is no direct finding suggesting whether this coping strategy has a positive or negative impact for the YC. Further research is warranted.

Engaging with friends as a way to cope with caregiving stress is an emotion-focused strategy. YCs have expressed that friends are a vital part of their social life, and that if they do choose to share their caregiving role with anyone it is often with friends (Aldridge & Becker, 1993; O'Dell et al., 2010). This creates an interesting conflict for YCs as they might not want to share their caregiving role with others but want to spend time with their friends when they are stressed. This could suggest that YCs may not share their caregiving role with their friends but spend time with friends as an avoidance of their home-life stressors. Through this lens, it is possible that spending time with friends could be a disengagement coping strategy. Further analysis discovered a significant positive correlation between this coping strategy and the social recognition stress scale, indicating the more they use this type of coping strategy, the more stress they experience related to social recognition. Further examination of this relation and use of this strategy is needed to more fully understand its role.

It was hypothesized that YCs would most frequently use emotion-focused disengagement and emotion-focused engagement strategies. Three of the five top stressors were within these categories, partially supporting the initial hypothesis. Within the adult caregiving literature,

avoidance or disengagement type coping are used more often for caregivers possibly due to the lack of personal resources and the lack of control in types of stressors caregivers experience (Roth & Cohen, 1986; Samuels-Dennis, 2007). Depending on the caregiver's perceived control over the stressor, stress and anxiety may be reduced with this coping strategy. If there is no control in the situation, then it creates a challenge for caregivers to use more problem-solving coping or engagement coping as there is little change that can be done (Roth & Cohen, 1986). It is also possible for the level of burden to impact the way a caregiver chooses to cope which can lead to more avoidance coping (Abrudan & Virga, 2014). Further, Pakenham et al. (2006) suggested that caregivers may use more reactive coping and less problem solving due to the unpredictability of the caregiving role. YCs must exercise caution when using these coping strategies as negative outcomes are associated with avoidance type strategies such as emotional numbness or not recognizing possible solutions (Roth & Cohen, 1986).

Correlation Analyses Results

It was hypothesized that problem-focused coping engagement would be a moderator between stress and anxiety, and stress and loneliness. It was also hypothesized that emotion-focused engagement coping would be a moderator between stress and depression and stress and self-esteem. No hypotheses were supported. This may be due to two main factors. First, significant correlations were not found between four cases between coping strategies and outcomes. Second, the small sample size reduced the possibility of significant findings. Previous research has found challenges in identifying specific coping categories as mediators and moderators in relation to stress. Often research has demonstrated a lack of power due to low numbers of participants, other variables at play, or the way coping was measured can contribute to coping not being found as a moderator. Many studies found no moderation qualities for coping

in a variety of caregiving contexts (Abrudan & Virga, 2014; Pot, Deeg, & van Dyck, 2000; Samuels-Dennis, 2007).

The first unexpected result was the lack of a significant relation between emotion-focused engagement and overall self-esteem. This could be because self-esteem is more an internal function, with some dependence on social interaction, but is predominantly an internal thinking or understanding of yourself. This may limit the relation of self-esteem to emotion-focused engagement, as the subscales are express emotions and social support. This could be the case because if self-esteem is more of an internal process, it may not have a direct link with expressing emotions outwardly or seeking social support as these are both external ways to cope. In contrast, Sexton et al. (2018) found emotion-focused coping is a better predictor for the relation between stress and self-esteem rather than problem-focused coping. These results contradict the current finding as this is suggesting self-esteem is not linked with emotion-focused engagement. It would be interesting in future research to uncover other variables that may explain why there is a lack of relationship between self-esteem and emotion-focused engagement coping.

Two of the other relations that were not significant were overall aversion to loneliness and both disengagement coping strategies. It is interesting to note that Sexton et al. (2018) determined that aversion to loneliness was found not to be related to any of the coping strategies including emotion-focused, problem-focused, and avoidance-focused coping. Schoenmakers, van Tilburg, and Fokkema (2015) also demonstrated two pathways of using emotion-focused and problem-focused coping in relation to loneliness. The results by Schoenmakers et al. (2015) suggested that a way to use problem-focused coping to decrease loneliness would be to focus on improving one's relationships. A different way to alleviate loneliness would be to use emotion-focused coping by readjusting the expectations of the relationship. However, this could justify

why there is no relation in the current research as these forms of coping in relation to loneliness are both engagement coping strategies. Schoenmakers et al. suggest that if loneliness is a consistent problem then it may be more likely to lower one's expectations of relationships rather than try to fix them. This could allow for a possible explanation for the lack of significance between disengagement coping and loneliness as specific disengagement coping strategies (i.e., problem avoidance, wishful thinking, self-criticism, and social withdrawal) have limited association with an aversion to being alone (Revenson, 1981). Further, Revenson (1981) found that loneliness was related to the intensity of coping but not the type of coping strategy used (i.e. emotion-focused, problem-focused). In addition, the lack of significance could be due to the specificity of the coping strategies and the items that were selected for the purposes of this research.

The final relation that was found not to be significant was emotion-focused engagement (e.g., social support and expressing your emotions) and affinity to be alone. A preference to be alone rather than seek social support or express one's emotions would less likely be used. Affinity for being alone is not categorized as an emotion-focused engagement coping strategy (Tobin et al., 1982), however earlier findings suggest that affinity to being alone could be qualified as a prosocial coping strategy.

Moderation Model Results

Abrudan and Virga (2014) found that emotion-focused and problem-focused coping were not moderators when looking at caregiver burden and psychological distress within an adult caregiver population. Consistent with current findings, significant correlations were found between the different coping strategies and the independent variable (i.e. caregiver burden; overall stress), but there were no significant results for coping as a moderator; it was suggested within this research that it could be outside factors such as the level of burden, stress appraisal,

or breadth of coping. The moderator could be related to the actual appraisal of the stressor rather than the coping strategy itself. Morano (2003) suggests focusing interventions on how caregivers appraise stress could help empower caregivers to choose the best coping strategy for their situation. This could explain why, as the actual appraisal of whether anything can be done to change the stressor determines what types of coping strategy will be used (i.e., emotion-focused or problem-focused). Furthering this idea, it could also be that the breadth of coping is more impactful, meaning the more forms of coping you use the better your outcome. Previous research has explored variability of coping strategies in relation to stress and psychosocial outcomes (Samuels-Dennis, 2007). Follow-up analyses were run to examine possible explanations; it was interesting to find that there was a significant relation between breadth of coping and three of the psychosocial outcomes, meaning as the number of coping strategies increased so did depressive symptoms, anxiety, and loneliness levels. A significant relation between breadth of coping and self-esteem was not found. This suggests the possibility that coping did not fit the scale categorization but rather is a continuum of effectiveness dependent on the types of stressors.

Another possible explanation for the lack of findings could be due to individual differences relating to how an individual may cope with stress, such as personality. Previous research by Connor-Smith and Flachsbart (2007) suggested a predictive relationship between personality traits and different coping strategies. An example is those with higher extraversion and conscientiousness can predict problem-solving and cognitive restructuring forms of coping, whereas it was found that neuroticism predicted emotion-focused coping such as wishful thinking and withdrawal. However, both extraversion and neuroticism were a predictor for seeking social support as a coping strategy (Connor-Smith & Flachsbart, 2007). This could demonstrate fundamental differences in personality that could lead to different ways of coping that could moderate the effect between stress and negative outcomes. It is possible that innate

personality traits may directly link to how an individual copes, and indirectly link with the outcomes associated with that coping strategy. Future research should explore how personality may play a role in the complex relation between stress, coping, and psychosocial outcomes.

Another possible moderator relating to individual difference could be the YCs' level of self-efficacy. Within the caregiving context, self-efficacy is defined as "the belief in the ability to carry out different activities related to caregiving" (Romero-Moreno et al., 2011, p. 221). Self-efficacy in previous research has been shown to be a moderator between stress and distress outcomes including depression and anxiety (Romero-Moreno et al., 2011). Tang et al. (2015) found that the manner in which the stress is appraised could affect the level of confidence that caregivers may have. This suggests the more confidence caregivers have, the less stressed they will be, which could lead to lower depressive symptoms (Tang et al., 2015). Further, research by Romero-Moreno et al. (2011) specifically looks at when caregivers have high burden scores, how self-efficacy, relating to control for upsetting thoughts, can affect distress outcomes. This demonstrates that self-efficacy can affect the overall stress levels of a caregiver but can also allow for effective coping mechanisms such as controlling upsetting thoughts. Overall, the results demonstrate the complex relation between stress, coping, and psychosocial outcomes. It suggests that it may not be a simple equation of if one copes this way it will lead to better outcomes; instead, it may actually demonstrate the unique context of YCs.

Limitations

There are a few limitations within the current research that should be identified. First, this study used purposive sampling and was exploratory; therefore, it cannot be generalized. It does however provide insight into the experience of a caregiver role. Second, the majority of participants were part of a YC support program. While efforts were made to recruit those with minimal exposure to the program, this sample could have a more developed understanding about

coping strategies due to life skill development programs offered. However, length of time in the program did not seem to influence the use of effective coping strategies. Third, even though power analysis determined the need for 55 participants to have enough statistical power and that number was met, there may not have been enough power to detect possible moderation effects. However, due to the hidden nature of this population, this study offers an unique opportunity for exploration of a little understood group. Fourth, self-reports were used; however, research has shown that when participants are assured of confidentiality they answer truthfully (Murray & Perry, 1987; White, 1991). Specific procedures were put into place to assure participants of the confidential nature of this study, thereby reducing inaccuracy of data. Finally, scales used were adapted and shortened to reduce fatigue during data collection. Items selected by the research team may not have given a comprehensive examination of each construct. This study is one of few studies to examine these issues within a YC population, providing valuable insights into potential supports required.

Implications

The current study examined causes of YCs' stress and coping strategies. Social recognition of the role and having validation and recognition for their extra responsibilities appear to be critical for reducing YCs' stress. Three main implications can be developed from the current results:

1. Policy: The results from this research highlight the need for policy reform, as the key stressors are within social recognition and school settings. Within the school setting it is critical to allow for further teacher training to develop more awareness of YCs and ways to identify YCs within the classroom. Other policies should be created within the school setting to reduce stress regarding school assignments for identified YCs and give YCs a chance to explain if there are other reasons their homework might not be complete.

Further, policy needs to be developed at regional, provincial, and federal levels to identify YCs within legislation as a formal caregiving category. If YCs are identified formally, then they will be able to have access to funding and more supports to help with their stress and develop their coping toolkit. The results demonstrate YCs are stressed about not being recognized or validated within or outside of their family and policy development is a systematic way to highlight what YCs do for their families.

2. **Awareness Campaigns:** Awareness campaigns can highlight the importance of the YC role, thus increasing recognition for the kinds of activities involved in caregiving. This research also revealed the importance of awareness of YCs within the school and general community, as YCs do not feel recognized for what they do within their family. A school campaign would help educators and support workers become aware of YCs in order to identify and further support YCs' needs. It could also help YCs to not worry about others finding out about their caregiving role and instead feel supported and celebrated for what they do in their family. Awareness campaigns within the community setting could increase general awareness which could then make YCs feel more validated in their role as others know YCs do exist and are caring for someone in their family.
3. **Program Development:** The results suggest the need for support programs designed to help YCs feel validated and capable so positive outcomes can be developed. The results in this research suggest that programs need to be developed with the information that YCs use a lot of avoidance or disengagement type coping strategies and often try to ignore the problems they are having. This is crucial to know a baseline of coping strategies that YCs use and then cater programs around this information. This could allow for programs to be developed to help YCs learn different types of coping to use in

different situations. Further, the research also justifies the need for programs to teach a variety of coping strategies in order to be able to meet different forms of stress that are experienced by YCs.

Future Research

Future research is needed that corresponds to stress and coping within the YC context. There are a variety of negative outcomes associated with increased stress due to the caregiving role, such as depressive symptoms, anxiety, lower self-esteem, and loneliness (Charles et al., 2008; Collins & Bayless, 2013; Frank et al., 1999; Lakman & Chalmers, 2018; Sahoo & Suar, 2010). Future research should look at ways to help understand the YC context and how to decrease the negative impacts of the role, including the following:

1. Future research should explore how YC stressors and normative stressors of YCs interact and if these stressors affect YCs in different ways. In addition, it would be beneficial to do a comparative analysis on these variables between YCs and non-YCs to understand how YCs may experience stress differently and may cope in different ways.
2. Future research should look into why self-esteem and loneliness were not associated with certain coping strategies. These results were surprising in light of past research and need to be further explored to understand if these constructs do not relate to coping or if there are other possible reasons why no relation was found.
3. The results did not uncover what types of coping are most effective for different outcomes. Future research should explore what type of coping is most effective for different forms of stress. It may be that more individual plans may need to be developed for each YC depending on the types of stressors and what coping strategies are effective

for that individual. It is imperative to understand the role coping plays between stress and negative outcomes to help decrease the negative impact of the caregiving role.

4. Finally, research is needed to understand what other variables may interact with stress and negative outcomes such as personality traits or self-efficacy. It is critical for future research to explore this dynamic relationship in order to address the stressful situation of young caregiving.

Strengths

There are some key strengths within this research study. The main strength of this study is that it has allowed for a deeper understanding of YCs in the context of stress, coping, and psychosocial outcomes in general. However, there are also a few other specific strengths to highlight.

Firstly, a key strength for this study is the sample size. Although, limited power impacted the moderation results, 58 YCs is a substantial sample size due to the hidden nature of the population. The study's sample population of 58 YCs allowed for an exploration into what causes YCs stress and what forms of coping they currently use in their lives.

Secondly, another strength was the scales selected for this research study. This study was one of the first studies to use the Perceived Impact of Child Caregiving Scale in a Canadian context. This is a strength, as rather than just using a normative stressor scale, this scale shows what causes stress to YCs within the caregiving role and how it impacts their lives. The use of different psychosocial outcomes is an additional strength as it helps to determine the relations between stress and each of these outcomes rather than just overall outcomes such as adjustment.

Thirdly, a final key strength of this research is that its use of these scales within the Canadian context allows for YC support programs to develop programs corresponding to what

causes YCs' stress. Further the results show the types of coping strategies used most frequently are more avoidance-type coping strategies, which can foster the development of coping skill programs to increase YCs' use of proactive coping and less reliance on avoidance.

Conclusion

YCs have an important role within their family. The current research study provided a deeper understanding of the YC context including who they care for, the reason for caring, and the types of responsibilities they do within their home. The results revealed that YCs want to be validated and recognized within multiple contexts for the role they play in their family. This suggests a need for general awareness about the YC role, recognition in their families, their schools, and their community. Results demonstrated also that YCs use predominately disengagement coping strategies suggesting a need for coping skill development programs to teach positive ways to cope. While the current study found a strong relationship between YC stress and negative psychosocial outcomes, the coping strategies explored did not moderate the impact of the stressors. Further research is needed to understand the complex relation among stress, coping, and psychosocial outcomes. This study has provided clear direction for programs, services, and policy makers in assisting to reduce the possible negative impacts associated with the YC role.

References

- Abrudan, D., & Virga, D. (2014). The moderators of the relationship between burden and psychological distress among caregivers: Depression symptoms and coping strategies. *Psihologia Resurselor Umane, 12*(2), 101-113.
- Aldridge, J., & Becker, S. (1993). *Children who care: Inside the world of young carers*. Loughborough, England: Loughborough University.
- Aronson, J. (1992). Women's sense of responsibility for the care of old people: "But who else is going to do it?" *Gender & Society, 6*(1), 8-29. doi:10.1177/089124392006001002
- Banks, P., Cogan, N., Riddell, S., Deeley, S., Hill, M., & Tisdall, K. (2002). Does the covert nature of caring prohibit the development of effective services for young carers? *British Journal of Guidance & Counselling, 30*(3), 229-246. doi:10.1080/030698802100002281
- Becker, S. (2007). Global perspectives on children's unpaid caregiving in the family: Research and policy on "young carers" in the UK, Australia, the USA and Sub-Saharan Africa. *Global Social Policy, 7*(1), 23-50. doi:10.1177/1468018107073892
- Belansky, E. S., & Boggiano, A. K. (1994). Predicting helping behaviours: The role of gender and instrumental/expressive self-schemata. *Sex Roles, 30*(9-10), 647-661. doi:10.1007/BF01544668
- Bolas, H., Van Wersch, A., & Flynn, D. (2007). The well-being of young people who care for a dependent relative: An interpretative phenomenological analysis. *Psychology and Health, 22*(7), 829-850. doi:10.1080/14768320601020154
- Chalmers, H. (2004). *A comprehensive examination of adolescent gambling* (Unpublished doctoral dissertation). Brock University, St. Catharines, ON.

- Chalmers, H., & Lucyk, L. (2012). The impact of caregiving: Is it who I am or what I do? *Child and Youth Care Practice, 25*(2), 37-46.
- Charles, G., Stainton, T., & Marshall, S. (2008). Young carers in Canada: An invisible population. *Relational Child and Youth Care Practice, 21*(4), 5-12.
- Chen, H., Huang, M., Yeh, Y., Huang, W., & Chen, C. (2015). Effectiveness of coping strategy intervention on caregiver burden among caregivers of elderly patients with dementia. *Psychogeriatrics, 15*(1), 20-25. doi:10.1111/psyg.12071
- Cohen, S. A., Cook, S., Kelley, L., Sando, T., & Bell, A. E. (2015). Psychosocial factors of caregiver burden in child caregivers: Results from the new national study of caregiving. *Health & Quality of Life Outcomes, 13*(1), 120-125. doi:10.1186/s12955-015-0317-2
- Collins, J., & Bayless, S. (2013). How caring for a parent affects the psychosocial development of the young. *Nursing Children & Young People, 25*(10), 16-21.
doi:10.7748/ncyp2013.12.25.10.16.e351
- Connor-Smith, J. K., & Flachsbart, C. (2007). Relations between personality and coping: A meta-analysis. *Journal of Personality and Social Psychology, 93*(6), 1080-1107.
doi:10.1037/0022-3514.93.6.1080
- Cooper, C., Katona, C., Orrell, M., & Livingston, G. (2008). Coping strategies, anxiety and depression in caregivers of people with Alzheimer's disease. *International Journal of Geriatric Psychiatry, 23*(9), 929-936. doi:10.1002/gps.2007
- Dwyer, J. W., & Secombe, K. (1991). Elder care as family labor: The influence of gender and family position. *Journal of Family Issues, 12*(2), 229-247.
doi:10.1177/019251391012112006

- Earley, L., Cushway, D., & Cassidy, T. (2007). Children's perceptions and experiences of caregiving: A focus group study. *Counseling Psychology Quarterly*, 20(1), 69-80.
doi:10.1080/09515070701217830
- Early, L., Cushway, D., & Cassidy, T. (2006). Perceived stress in young carers: Development of a measure. *Journal of Child and Family Studies*, 15(2), 169-180. doi:10.1007/s10826-005-9011-z
- Eley, S. (2004). "If they don't recognize it, you've got to deal with it yourself": Gender, young caring and educational support. *Gender and Education*, 16(1), 65-75.
doi:10.1080/0954025032000170345
- Evans, L. D., Kouros, C., Frankel, S. A., McCauley, E., Diamond, G. S., Scholeredt, K. A., & Garber, J. (2015). Longitudinal relations between stress and depressive symptoms in youth: Coping as a mediator. *Journal of Abnormal Child Psychology*, 43(2), 355-368.
doi:10.1007/s10802-014-9906-5
- Ferrara, M., Langiano, E., Di Brango, T., De Vito, E., Di Cioccio, L., & Bauco, C. (2008). Prevalence of stress, anxiety and depression in with Alzheimer caregivers. *Health and Quality of Life Outcomes*, 6(93), 1-5. doi:10.1186/1477-7525-6-93
- Folkman, S., & Lazarus, R. S. (1981). An analysis of coping in a middle aged community sample. *Journal of Health and Social Behaviour*, 21(3), 219-239.
- Frank, J., Tatum, C., & Tucker, S. (1999). *On small shoulders: Learning from the experiences of former young carers*. London, England: The Children's Society.
- Frant, I. A. (2016). Implications of self-esteem in adolescence. *Journal Plus Education*, 14(1), 90-99. Retrieved from <http://www.uav.ro/jour/index.php/jpe/article/view/635/697>

- Garber, J. (2015). Longitudinal relations between stress and depressive symptoms in youth: Coping as a mediator. *Journal of Abnormal Child Psychology*, *43*(2), 55-368.
doi:10.1007/s10802-014-9906-5
- Garcia-Alberca, J. M., Cruz, B., Lara, J. P., Garrido, V., Gris, E., Lara, A., & Castilla, C. (2012). Disengagement coping partially mediates the relationship between caregiver burden and anxiety and depression in caregivers of people with Alzheimer's disease. Results from the MALAGA-AD study. *Journal of Affective Disorders*, *136*(3), 848-856.
doi:10.1016/j.jad.2011.09.026
- Gonzalez-Salvador, M. T., Arango, C., Lyketsos, & C. G., Barba, A. C. (1999). The stress and psychological morbidity of the Alzheimer patient caregiver. *International Journal of Geriatric Psychiatry*, *14*(9), 701-710. doi:10.1002/(SICI)1099-1166(199909)14:9<701::AID-GPS5>3.0.CO;2-#
- Government of Canada. (2017). *Benefits for caregivers*. Retrieved from <http://www.canada.ca/en/financial-consumer-agency/services/caring-someone-ill/benefits-tax-credits-caregivers.html>
- Hayes, A. F. (2012). *PROCESS: A versatile computational tool for observed variable mediation, moderation, and conditional process modeling* [White paper]. Retrieved from <http://tiny.cc/6xwdqy>
- Hayslip, B. J., Han, G., & Anderson, C. L. (2008). Predictors of Alzheimer's disease caregivers depression and burden: What noncaregiving adults can learn from active caregivers. *Educational Gerontology*, *34*(11), 945-969. doi:10.1080/03601270802016481
- Hequembourg, A., & Brailier, S. (2005). Gendered stories of parental caregiving among siblings. *Journal of Aging Studies*, *19*(1), 53-71. doi:10.1016/j.jaging.2003.12.001

- Joseph, S., Becker, S., Becker, F., & Regel, S. (2009). Assessment of caring and its effects in young people: Development of the multidimensional assessment of caring activities checklist (MACA-YC18) and the positive and negative outcomes of caring questionnaire (PANOC-YC20) for young carers. *Child: Care, Health & Development*, 35(4), 510-520. doi:10.1111/j.1365-2214.2009.00959.x
- Kumar, S. P., & Raja, B. D. (2009). High self-esteem as a coping strategy for students with learning disabilities. *Journal on Educational Psychology*, 2(4), 14-19. Retrieved from <https://eric.ed.gov/?id=EJ1097813>
- Lackey, N. R., & Gates, M. F. (2001). Adults' recollections of their experiences as young caregivers of family members with chronic physical illnesses. *Journal of Advanced Nursing*, 34(3), 320-328. doi:10.1046/j.1365-2648.2001.01761.x
- Lakman, Y. (2015). Profiling young carers' lives: An examination of individual, family, and social contexts (Master's thesis). Brock University, St. Catharines, ON. Retrieved from <https://dr.library.brocku.ca/handle/10464/7156>
- Lakman, Y., & Chalmers, H. (2018). *Creating a young carer profile: Exploring similarities and differences between carers and non-carers*. Manuscript submitted for publication.
- Lakman, Y., Chalmers, H., & Sexton, C. (2017). Young carers' educational experiences and support: A roadmap for the development of school policies to foster their academic success. *Alberta Journal of Educational Research*, 61(3), 63-74.
- Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal and coping*. New York, NY: Springer.
- Llanque, S., Savage, L., Rosenburg, N., & Caserta, M. (2016). Concept analysis: Alzheimer's caregiver stress. *Nursing Forum*, 51(1), 21-31. doi:10.1111/nuf.12090

- Mansell, N. (2016). *Knowledge is power: Let's talk about young carers*. Unpublished manuscript, Brock University, St. Catharines, ON.
- Marcoen, A., Goossens, L., & Caes, P. (1987). Loneliness in pre-thought late adolescence: Exploring the contributions of a multidimensional approach. *Journal of Youth and Adolescence, 16*, 561-577. doi:10.1007/BF02138821
- Mausbach, B. T., Roepke, S. K., Chattillion, E. A., Harmell, A. L., Moore, R., Romero-Moreno, R., Bowie, C. R., & Grant, I. (2012). Multiple mediators of the relations between caregiving stress and depressive symptoms. *Ageing & Mental Health, 16*(1), 27-38. doi:10.1080/13607863.2011.615738
- McDonald, J., Cumming, J., & Dew, K. (2009). An exploratory study of young carers and their families in New Zealand. *Journal of Social Sciences, 4*(2), 115-129. doi:10.1080/1177083X.2009.9522448
- McDonald, J., Dew, K., & Cumming, J. (2010). Change and adaptation in families with young carers. *Australian Journal of Social Issues, 45*(4), 459-475. doi:10.1002/j.1839-4655.2010.tb00192.x
- Moore, T., McArthur, M., & Morrow, R. (2009). Attendance, achievement and participation: Young carers' experiences of school in Australia. *Australian Journal of Education, 53*(1), 5-18. doi:10.1177/000494410905300102
- Morano, C. L. (2003). Appraisal and coping: Moderators or mediators of stress in Alzheimer's disease caregivers? *Social Work Research, 27*(2), 116-128. doi:10.1093/swr/27.2.116
- Nagl-Cupal, M., Daniel, M., Koller, M. M., & Mayer, H. (2014). Prevalence and effects of caregiving on children. *Journal of Advanced Nursing, 70*(10), 2314-2325. doi:10.1111/jan.12388

- O'Dell, L. O., Crafter, S., de Abreu, G., & Cline, T. (2010). Constructing "normal childhoods": Young people talk about young carers. *Disability & Society, 25*(6), 643-655.
- Pakenham, K. I., Chiu, J., Bursnall, S., & Cannon, T. (2007). Relations between social support, appraisal and coping and both positive and negative outcomes in young carers. *Journal of Health Psychology, 12*(1), 89-102. doi:10.1177/1359105307071743
- Pakenham, K. I., Chiu, J., Bursnall, S., Cannon, T., Okachi, M. (2006). The psychosocial impact of caregiving on young people who have a parent with an illness or disability: Comparisons between young caregivers and noncaregivers. *Rehabilitation Psychology, 51*(2), 113-126. doi:10.1037/0090-5550.51.2.113
- Pot, A. M., Deeg, D. J. H., & van Dyck, R. (2000). Psychological distress of caregivers: Moderator effects of caregiver resources? *Patient Education and Counseling, 41*(2), 235-240. doi:10.1016/S0738-3991(99)00081-6
- Revenson, T. A. (1981). Coping with loneliness: The impact of causal attributions. *Personality and Social Psychology Bulletin, 7*(4), 565-571. doi:10.1177/014616728174007
- Robinson, K. M., Buckwalter, K., & Reed, D. (2013). Differences between dementia caregivers who are users and nonusers of community services. *Public Health Nursing, 30*(6), 501-510. doi:10.1111/phn.12041
- Romero-Moreno, R., Losada, A., Mausbach, B. T., Marquez-Gonzalez, M., Patterson, T. L., & Lopez, J. (2011). Analysis of the moderating effect of self-efficacy domains in different points of the dementia caregiving process. *Aging & Mental Health, 15*(2), 221-231. doi:10.1080/13607863.2010.505231
- Rose, H. & Cohen, K. (2010). The experiences of young carers: A meta-synthesis of qualitative findings. *Journal of Youth Studies, 13*(4), 473-487. doi:10.1080/13676261003801739

- Rosenberg, M. (1965). *Society and the adolescent self-image*. Princeton, NJ: Princeton University Press.
- Roth, S., & Cohen, L. J. (1986). Approach, avoidance, and coping with stress. *American Psychologist*, *41*(7), 813-819. doi:10.1037/0003-066X.41.7.813
- Sahoo, R., & Suar, D. (2010). Influence of social environment on young carers, assistance and consequences of caregiving. *Psychological Studies*, *55*(4), 323-329. doi:10.1007/s12646-010-0041-2
- Samuels-Dennis, J. (2007). Employment status, depressive symptoms, and the mediating/moderating effects of single mothers coping repertoire. *Public Health Nursing*, *24*(6), 491-502.
- Schoenmakers, E. C., van Tilburg, T. G., & Fokkema, T. (2015). Problem-focused and emotion-focused coping and loneliness: How are they related? *European Journal of Ageing*, *12*(2), 153-161. doi:10.1007/s10433-015-0336-1
- Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *The American Journal of Nursing*, *108*, 23-27.
doi:10.1097/01.NAJ.0000336406.45248.4c
- Sexton, C., Chalmers, H., & Lakman, Y. (2018). *Stressed out? The stress of responsibilities in young carers and implications of coping on psychosocial outcomes*. Manuscript submitted for publication.
- Shifren, K., & Kachorek, L. V. (2003). Does early caregiving matter? The effects on young caregivers' adult mental health. *International Journal of Behavioral Development*, *27*(4), 338-346. doi:10.1080/01650250244000371

- Smyth, C., Blaxland, M., & Cass, B. (2011). “So that’s how I found out I was a young carer and that I actually had been a carer most of my life”: Identifying and supporting hidden young carers. *Journal of Youth Studies, 14*(2), 145-160.
doi:10.1080/13676261.2010.506524
- Spence, S. H. (1998). A measure of anxiety symptoms among children. *Behavior Research and Therapy, 36*(5), 545-566. doi:10.1016/S0005-7967(98)00034-5
- Stamatopoulos, V. (2015). One million and counting: The hidden army of young carers in Canada. *Journal of Youth Studies, 18*(6), 809-822. doi:10.1080/13676261.2014.992329
- Stamatopoulos, V. (2016). Supporting young carers: A qualitative review of young carer services in Canada. *International Journal of Adolescence and Youth, 21*(2), 178-194.
doi:10.1080/02673843.2015.1061568
- Synes-Taraba, L. (2008). *The caring responsibilities of young carers in the Niagara Region with a focus on gender*. Unpublished manuscript, Brock University, St. Catharines, ON.
- Tang, F., Jang, H., Lingler, J., Tamres, L. K., & Erlen, J. A. (2015). Stressors and caregivers’ depression: Multiple mediators of self-efficacy, social support, and problem-solving skill. *Social Work in Health Care, 54*(7), 651-655. doi:10.1080/00981389.2015.1054058
- Thomas, N., Stainton, T., Jackson, S., Wai Vee, C., Doubtfire, S., & Webb, A. (2003). “Your friends don’t understand”: Invisibility and unmet need in the lives of “young carers.” *Child & Family Social Work, 8*(1), 35-46. doi:10.1046/j.1365-2206-2003-00266.x
- Tobin, D. L., Holroyd, K. A., & Reynolds, R. (1982, November). *The assessment of coping: Psychometric development of the coping strategies inventory*. Paper presented at the meeting of the Association for the Advancement of Behavior Therapy, Los Angeles, CA.

Warren, J. (2007). Young carers: Conventional or exaggerated levels of involvement in domestic and caring tasks? *Children & Society*, *21*(2), 136-146. doi:10.1111/j.1099-

0860.2006.00038.x

Weissman, M. M., Orvaschel, H., & Padian, N. (1980). Children's symptom and social functioning self-report scales: Comparison of mothers' and children's reports. *Journal of Nervous Mental Disorders*, *168*(12), 736-740.

Appendix A

Demographics Section of the Questionnaire

Demographics

Part A: Please fill in the circle that best describes you.

1. Are you male or female?

- Male Female

2. How old are you?

- | | | |
|-----------------------------------|--------------------------|------------------------------------|
| <input type="radio"/> 9 and under | <input type="radio"/> 13 | <input type="radio"/> 17 |
| <input type="radio"/> 10 | <input type="radio"/> 14 | <input type="radio"/> 18 |
| <input type="radio"/> 11 | <input type="radio"/> 15 | <input type="radio"/> 19 and older |
| <input type="radio"/> 12 | <input type="radio"/> 16 | |

3. Do you go to Powerhouse Project?

- Yes
 No

4. How long have you been going to Powerhouse Project?

- | | |
|--|-------------------------------|
| <input type="radio"/> Less than a year | |
| <input type="radio"/> 1 year | <input type="radio"/> 6 years |
| <input type="radio"/> 2 years | <input type="radio"/> 7 years |
| <input type="radio"/> 3 years | <input type="radio"/> 8 years |
| <input type="radio"/> 4 years | <input type="radio"/> 9 years |
| <input type="radio"/> 5 years | |

5. Do you live with a relative (parent/ grandparent, brother, sister or other family member) who is ill or disabled?

- Yes
 No
 Don't Know

6. Which of your relatives needs care/ assistance? Check all that apply.

- | | |
|-------------------------------|-----------------------------------|
| <input type="radio"/> Mother | <input type="radio"/> Aunt Uncle |
| <input type="radio"/> Father | <input type="radio"/> Grandfather |
| <input type="radio"/> Sister | <input type="radio"/> Grandmother |
| <input type="radio"/> Brother | <input type="radio"/> Other _____ |

7. Fill in beside the reason why each family member needs care.

- | | |
|---------------------------------------|--|
| <input type="radio"/> Alzheimer's | <input type="radio"/> Down's syndrome |
| <input type="radio"/> MS | <input type="radio"/> Autism |
| <input type="radio"/> Depression | <input type="radio"/> Language barrier |
| <input type="radio"/> Substance abuse | <input type="radio"/> Other _____ |

8. For approximately how many years have you been providing care?

9. Approximately how old were you when your relative began to need care/assistance?

10. On average, approximately how much time do you spend caring/ helping others in the home each day?

- Less than 1 hour
- 1-2 hours
- 3-4 hours
- 5-6 hours
- 7-8 hours
- 9 hours or more

11. Please circle the response that best applies to you for your responsibilities within the home

At home, are you expected to help with:	Rarely	Occasionally	Sometimes	Usually	Most of the time	Does not apply
Household tasks (e.g. laundry, house cleaning, gardening, etc)	1	2	3	4	5	6
Meal preparation	1	2	3	4	5	6
Helping brothers and sisters (e.g., help with homework, bedtime routine)	1	2	3	4	5	6
Personal care for the relative who needs care (i.e. help with bathing toileting, etc.)	1	2	3	4	5	6
Providing medical care for the relative who needs care (e.g., giving pills, giving needles, attending appointments)	1	2	3	4	5	6
Managing the house (e.g. paying bills)	1	2	3	4	5	6
Translation	1	2	3	4	5	6
Emotional support (e.g., spend time talking and listening to them, keeping the relative happy)	1	2	3	4	5	6
Other household activities: specify _____ _____	1	2	3	4	5	6

12. Do you think you are a young caregiver?

- Yes
- No
- Maybe
- Don't know

Appendix B

Certificate of Ethics Clearance



Brock University
 Research Ethics Office
 Tel: 905-688-5550 ext. 3035
 Email: reb@brocku.ca

Social Science Research Ethics Board

Certificate of Ethics Clearance for Human Participant Research

DATE: 4/10/2017
 PRINCIPAL INVESTIGATOR: CHALMERS, Heather - Child and Youth Studies
 FILE: 16-216 - CHALMERS
 TYPE: Masters Thesis/Project STUDENT: Cayleigh Sexton
 SUPERVISOR: Heather Chalmers
 TITLE: Stress and Coping within Caregiving Roles

ETHICS CLEARANCE GRANTED

Type of Clearance: NEW

Expiry Date: 4/30/2018

The Brock University Social Science Research Ethics Board has reviewed the above named research proposal and considers the procedures, as described by the applicant, to conform to the University's ethical standards and the Tri-Council Policy Statement. Clearance granted from 4/10/2017 to 4/30/2018.

The Tri-Council Policy Statement requires that ongoing research be monitored by, at a minimum, an annual report. Should your project extend beyond the expiry date, you are required to submit a Renewal form before 4/30/2018. Continued clearance is contingent on timely submission of reports.

To comply with the Tri-Council Policy Statement, you must also submit a final report upon completion of your project. All report forms can be found on the Research Ethics web page at <http://www.brocku.ca/research/policies-and-forms/research-forms>.

In addition, throughout your research, you must report promptly to the REB:

- a) Changes increasing the risk to the participant(s) and/or affecting significantly the conduct of the study;
- b) All adverse and/or unanticipated experiences or events that may have real or potential unfavourable implications for participants;
- c) New information that may adversely affect the safety of the participants or the conduct of the study;
- d) Any changes in your source of funding or new funding to a previously unfunded project.

We wish you success with your research.

Approved:

Ann-Marie DiBiase, Chair
 Social Science Research Ethics Board

Note: Brock University is accountable for the research carried out in its own jurisdiction or under its auspices and may refuse certain research even though the REB has found it ethically acceptable.

If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and clearance of those facilities or institutions are obtained and filed with the REB prior to the initiation of research at that site.

Appendix C

Consent Form

Participant Consent Form

Thanks for your interest in my study. I am asking you to be part of a study called “Stress and Coping within Caregiving Roles” to help me understand the experiences of children in caregiving roles. With your help, we will help Young Carer agencies better support you in your role.

You have chosen to complete a 30-minute survey in person. No one will be able to link your name to your answers. All of the surveys will be kept in a locked cabinet in my supervisor’s office and will be safely shredded after 5 years.

By being part of this study you could learn more about what causes you stress and how to deal with it. You will also be given support tools or programs for young people in similar situations to yourself. There is a small chance that you may feel a little down or upset by some of the questions. In the rare occasion that this may happen, you will be given contact information at the end of the survey to support services and people who can help.

Being part of this study is completely up to you. You do not have to answer any question(s) you do not want to answer. If you want to stop filling in the survey, you are free to do so and will not have any consequences. After you have handed in your survey you will not be able to take out your answers from the study as your name is not linked to the survey.

I will be reporting the results of this study at conferences and in academic journals. If you would like a summary of the results will, please fill in the separate form (See Appendix D) when you finish the survey and I will email you a summary sometime in Fall 2017.

If you have any questions about this study please contact me (chalmerslab@brocku.ca) or my supervisor Heather Chalmers (chalmerslab@brocku.ca). The study has been reviewed and received ethics clearance through the Research Ethics Board at Brock University [File# 16-216] If you have any comments or concerns about your rights as a research participant, please contact the Research Ethics Office at (905) 688-5550 Ext. 3035, reb@brocku.ca.

Please do not hesitate to ask me if you have any questions.

Cayleigh Sexton, MA candidate
Brock University
chalmerslab@brocku.ca
905-688-5550 ext 5545

Dr. Heather Chalmers
Brock University
chalmerslab@brocku.ca
905-688-5550 ext 5545

Please fill in the answers to the below

I would like to participate in this research

- Yes
- No

If yes, please answer and fill out the below sections

Age: _____

Signature: _____

Date: _____

Appendix D

Support Services Sheet

Thank you for sharing your experiences! If you feel a little down or upset by any of the questions, please see the supports and contact information available at the end of the survey. **If you have any questions feel free to contact me at chalmerslab@brocku.ca.**

Support Services

Kids Help Phone

Contact information

Phone Number: 1-800-668-6868

24 hours / 7 days a week

Online: <http://kidshelpphone.ca/Teens/AskUsOnline/Chat-counselling.aspx>

Online Live Chat Times: Wednesday to Sunday 6PM to 2AM

Pathstone Crisis Services

Phone Number: 1-800-263-4944

24 hours, 365 days a year

Young Carer Programs & Supports

Young Carers Initiative – Powerhouse Project

Website: <http://www.powerhouseproject.ca/>

Niagara Office

Serves St. Catharines, Niagara Falls, Welland, & Port Colborne

Phone Number: 905-397-4201

Haldimand-Norfolk Office

Serves Hagersville, Dunville, Delhi, & Simcoe

Phone Number: 905-768-4488

Young Carers Program

Serves Toronto

Phone Number: 416-364-1666

Website: <http://www.ycptoronto.com/index.html>

A note about coping

People use many different ways people deal with their stress. Here are some helpful ways to cope with stress.

Helpful ways to cope

- Talk to a friend about how your feeling
- Think of the problem in a different way
- Make a plan of action
- Express your emotions
- Talk to someone in a similar situation
- Change something to help the problem

Calming Skills

- Deep breathing
- Count to 10
- Take a mindful walk
- Yoga
- Take a drink of water
- Think of your favourite place
- Remember the words to a song you love
- Positive self-talk
- Take a shower or bath
- Take a break
- Calming Jar

Appendix E

Stress Measure

Please be as honest and accurate as you can throughout. Try not to let your response to one statement influence your responses to other statements. There are no “correct” or “incorrect” answers. Answer according to your own feelings, rather than how you think “most people” would answer.					
	I disagree a lot	I disagree a little	I neither agree nor disagree	I agree a little	I agree a lot
It bothers me that caring takes over everything in my life	1	2	3	4	5
It bothers me that I can't have a life of my own	1	2	3	4	5
I feel there is no break from caring	1	2	3	4	5
It's hard to get a rest from caring	1	2	3	4	5
I feel tired because of the caring I do	1	2	3	4	5
It bothers me what other kids will say if I take time off school	1	2	3	4	5
I am bothered that I have missed too much school	1	2	3	4	5
I worry that if I wasn't caring I wouldn't know what to do with myself	1	2	3	4	5
It bothers me what teachers will say if I fall behind in school	1	2	3	4	5
Getting teased about being a carer is a problem for me	1	2	3	4	5
It bothers me that I can't take part in clubs or activities after school.	1	2	3	4	5
Feeling different from other kids is a problem for me	1	2	3	4	5
It bothers me that my family argues about caring.	1	2	3	4	5
I feel left out in my family.	1	2	3	4	5
I don't know where I belong in my family.	1	2	3	4	5
It bothers me that people never say that they are pleased with my caring	1	2	3	4	5
It bothers me that other people don't understand what I do to help my family	1	2	3	4	5
I think I work hard at caring but nothing seems to change	1	2	3	4	5
The people that I know understand about my caring.	1	2	3	4	5

Appendix F

Coping Strategies Measure

Instructions: Take a minute to choose a stressful caregiving situation and as you read through the following items, please answer them based on how you handled your event.					
	Not at all	A Little	Somewhat	Much	Very much
I just concentrated on what I had to do next; the next step	0	1	2	3	4
I hoped the problem would take care of itself	0	1	2	3	4
I went along as if nothing were happening	0	1	2	3	4
I realized that I brought the problem on myself	0	1	2	3	4
I told myself things that helped me feel better	0	1	2	3	4
I talked to someone about how I was feeling	0	1	2	3	4
I blamed myself	0	1	2	3	4
I made a plan of action and followed it	0	1	2	3	4
I wished that the situation would go away or somehow be over with	0	1	2	3	4
I let my feelings out somehow	0	1	2	3	4
I didn't talk to other people about the problem	0	1	2	3	4
I let my emotions out	0	1	2	3	4
I spent some time by myself	0	1	2	3	4
I stepped back from the situation and put things into perspective	0	1	2	3	4
My feelings were overwhelming and they just exploded	0	1	2	3	4
I asked a friend or relative I respect for advice	0	1	2	3	4
I made light of the situation and refused to get too serious about it	0	1	2	3	4
I hoped that if I waited long enough, things would turn out OK.	0	1	2	3	4
I kicked myself for letting this happen	0	1	2	3	4
I worked on solving the problems in the situation	0	1	2	3	4
I reorganized the way I looked at the situation, so things didn't look so bad	0	1	2	3	4
I spent some time with my friends	0	1	2	3	4
I avoided thinking or doing anything about the situation	0	1	2	3	4
I did not let others know how I was feeling	0	1	2	3	4

Appendix G

Self-Esteem Measure

Instructions: Below is a list of statements dealing with your general feelings about yourself. Please indicate how strongly you agree or disagree with each statement.

	Strongly Agree	Agree	Disagree	Strongly Disagree
On the whole, I am satisfied with myself	1	2	3	4
At times I think I am no good at all	1	2	3	4
I feel that I have a number of good qualities	1	2	3	4
I am able to do things as well as most other people.	1	2	3	4
I feel I do not have much to be proud of	1	2	3	4
I certainly feel useless at times	1	2	3	4
I feel that I'm a person of worth, at least on an equal plane with others	1	2	3	4
I wish I could have more respect for myself	1	2	3	4
All in all, I am inclined to feel that I am a failure	1	2	3	4
I take a positive attitude toward myself.	1	2	3	4

Appendix H

Depressive Symptoms Measure

Instructions: Below is a list of the ways you might have felt or acted. Please check how much you have felt this way during the past week.				
	Not At All	A Little	Some	A Lot
I was bothered by things that usually don't bother me	0	1	2	3
I did not feel like eating, I wasn't very hungry.	0	1	2	3
I wasn't able to feel happy, even when my family or friends tried to help me feel better	0	1	2	3
I felt like I was just as good as other kids	0	1	2	3
I felt like I couldn't pay attention to what I was doing	0	1	2	3
I felt down and unhappy	0	1	2	3
I felt like I was too tired to do things	0	1	2	3
I felt like something good was going to happen	0	1	2	3
I felt like things I did before didn't work out right	0	1	2	3
I felt scared	0	1	2	3
I didn't sleep as well as I usually sleep	0	1	2	3
I was happy	0	1	2	3
I was more quiet than usual	0	1	2	3
I felt lonely, like I didn't have any friends	0	1	2	3
I felt like kids I know were not friendly or that they didn't want to be with me	0	1	2	3
I had a good time	0	1	2	3
I felt like crying	0	1	2	3
I felt sad	0	1	2	3
I felt people didn't like me	0	1	2	3
It was hard to get started doing things	0	1	2	3

Appendix I
Anxiety Measure

Instructions: Please put a circle around the word that shows how often each of these things happen to you. There are no right or wrong answers.

	Never	Sometimes	Often	Always
I worry about things	0	1	2	3
When I have a problem, I get a funny feeling in my stomach	0	1	2	3
I feel afraid	0	1	2	3
I would feel afraid of being on my own at home	0	1	2	3
I worry about being away from my parents	0	1	2	3
I worry that something awful will happen to someone in my family	0	1	2	3
I have trouble going to school in the mornings because I feel nervous or afraid	0	1	2	3
When I have a problem, my heart beats really fast	0	1	2	3
I worry that something bad will happen to me	0	1	2	3
When I have a problem, I feel shaky	0	1	2	3
I would feel scared if I had to stay away from home overnight	0	1	2	3

Appendix J

Loneliness Measure

Instructions: For each statement below, circle the answer that best suits you.				
	Almost Never or Never	Sometimes	Often	Almost Always or Always
If I am lonely I go to see other people	1	2	3	4
I am unhappy when I have to do things on my own	1	2	3	4
If I am alone, I feel unhappy	1	2	3	4
If I feel bored , I feel lonesome	1	2	3	4
If I feel bored, I am unhappy	1	2	3	4
To really have a good time I have to be with my friends	1	2	3	4
If I am alone, I would like to have other people around	1	2	3	4
If I am lonely, I don't know what to do	1	2	3	4
To think something over, I want to be alone	1	2	3	4
If I have an argument with someone, I want to be alone to think it over	1	2	3	4
I am happy if I am the only one at home, because I can do some quiet thinking then	1	2	3	4
I want to be alone	1	2	3	4
I get away from others because they disturb me with their noise	1	2	3	4
Being along helps me renew my courage	1	2	3	4
I like to do things on my own at home	1	2	3	4
When I am alone, I quiet down	1	2	3	4