YOUNG CARERS IN CANADA: AN EXAMINATION OF THE PREVALENCE, POLICY AND PRACTICE OF YOUNG PEOPLE PROVIDING UNPAID CARE.

VIVIAN STAMATOPOULOS

A DISSERTATION SUBMITTED TO
THE FACULTY OF GRADUATE
STUDIES IN PARTIAL
FULFILLMENT OF THE
REQUIREMENTS FOR THE DEGREE
OF DOCTOR OF PHILOSOPHY

GRADUATE PROGRAM IN SOCIOLOGY
YORK UNIVERSITY
TORONTO, ONTARIO

January, 2018

Abstract

Despite the growing body of international research documenting the hidden lives of children and youth who provide substantial informal (unpaid) caregiving within their families, the Canadian literature continues to focus primarily on adult caregivers. This dissertation seeks to correct this gap by focusing on the unpaid care contributions provided by Canadian youth. To do so, a multimethod research design is used to explore four overriding research goals. First, a feminist political economy framework locates child and youth-based caregiving within the context of larger societal change triggered by advanced global capitalism. Second, a statistical trend analysis of youth caregiving based on available national datasets is presented to provide prevalence estimates as well as provincial and gendered variation in youth's caregiving. Third, the experiences of young carers are examined through focus groups held with those attending support programs for young carers. Fourth, interviews with program staff highlight the current state of policy and programming available to young carers across Canada. Results reveal that youth caregivers represent the third largest caregiver cohort across Canada, with important gendered and provincial differences. Focus groups reveal that young carers incur a unique form of "young carer penalty," affecting both their social and emotional well-being. Finally, the research finds that existing supports are both assistance and mitigation-based in nature, with current barriers to program growth linked to the lack of stable and sufficient funding from the state and a persistent inability to gain adequate entry into local schools in order to provide in-house programming. This research concludes with discussion of the policy and program issues related to the growing incidence of youth caregiving in Canada.

Dedication

The concept of opportunity costs is one that I am all too familiar with. Over the past decade, I have been a caregiver for my grandparents, helping them through multiple surgeries, cancer and the year-long intensive cancer treatment plan, diabetes and age-related blindness. I have been a personal shopper, financial advisor, transport specialist, healthcare coordinator, translation specialist, home cleaner, personal support worker and health and medical specialist. Our family doctor and I are on a text-message basis, I am the power of attorney for all decisions regarding my grandparents and the CCAC case managers know me by name. I talk to my grandfather, my best friend, about 10 times a day, often in relation to my required services for the following day and/or what is happening in the world of baseball.

Over the past year alone, my grandmother has undergone three surgeries, another three hospitalizations for pneumonia and a head injury from a nasty fall. My grandfather had two of his own hospitalizations and a very recent diagnosis of diabetes that needs to be monitored and managed. Limited mobility and language barriers require either myself or my mother to always be close by. I constantly worry about how they are and what may happen next and I never leave home for too long, regularly turning down out-of-town work and leisure opportunities to be on standby in case of emergency.

Of course, I love my grandparents and could not imagine *not* helping them. It has brought us closer together, developed a sense of empathy and respect for the needs and experiences of our senior population and made me all the more aware of the gaps in our current healthcare system. Canada is not ready or prepared to handle the looming aging crisis and that is a fact. My experiences and the experiences of many others, older and younger, can attest to that.

It is out of these experiences that this dissertation was motivated. Indeed, the need to rely on children, youth and other young adults to help fill the growing gaps in social reproductive labour is greater than ever before. We live in an era of steady welfare state retrenchment amidst significant demographic and socio-cultural change. Today, both parents are increasingly working to manage the growing costs of living and are doing so on declining incomes resulting from the rise of part-time, contract and temporary jobs fueled by globalization. Progressive reductions in public health and social care have meant that a growing responsibility for care is offloaded onto families through the shift from hospital to home-care and other related cutbacks. Add to this the declines in fertility amidst an ageing population and it becomes unsurprising that a growing burden of care has fallen on the Canadian children and youth who are seen as more flexible to pick up some of the care tab.

Problematically, these children, youth and young adults currently exist under the radar, unacknowledged by the Canadian state or broader public and unsupported in their caring roles. Knowing full well how my caregiving has impacted me over the past decade, a young woman with the knowledge to seek out assistance gained through my years of postsecondary education, I could not have imagined what it would have been like for a child or teenager fielding their way through adolescence. It is for these selfless young heroes that I dedicate this dissertation.

Acknowledgments

This work would not have been possible without the encouragement of many people in the Department of Sociology at York University and the amazing young carers and their dedicated supporters at the three existing Canadian young carer programs.

First and foremost, I must acknowledge Dr. Norene Pupo, who agreed to be my doctoral supervisor and who supported me throughout both my Masters and Doctoral studies. Norene, you have always been a true leader, mentor and friend and your warm guidance over the years has not gone unnoticed or unappreciated. I couldn't have asked for a more brilliant or wonderful advisor.

My dissertation committee members, Dr. Glenn J. Stalker and Dr. Nancy Mandell, have been extraordinary in guiding me through this process and lending their expertise during all stages of the process. Glenn, you helped develop my methodological skills through the years of coursework and paper collaborations and Nancy, you were instrumental in guiding my theoretical lens which most certainly helped steer me in the best possible direction. You have also been a warm and reliable confidant over the years and your mentorship has always been welcome and most appreciated. Furthermore, I would be remiss in leaving out the assistance I received from Dr. Mike Ornstein, whose expertise and assistance throughout my comprehensive and proposal stages helped foster a similar respect and love for all things survey research methodology.

Special mention must be given to the patience of my family and friends who have urged me along and upheld my sanity during periods of doctoral-induced insanity. You have all been instrumental to my success over the years. Finally, the exceptional support staff in our

department cannot be left out of consideration, especially the all-knowing and wonderful Audrey Tokiwa. I always look forward to seeing you and sharing some much appreciated laughs.

More than anyone, I thank my grandparents (my papoo and yaya) who have been the reason I embarked upon this dissertation. Their love and unconditional support means the world to me. I love you more than you can ever know.

TABLE OF CONTENTS

CHAPTER ONE

CHAPTER TWO

CHAPTER THREE

CHAPTER FOUR

The Hidden Army of Young Carers in Canada: A Statistical Overview of Caregiving among Canadian Youth Aged 15 to 24 ……………………………………….113

CHAPTER FIVE

The Benefits and Challenges of Youth-Based Caregiving: A first-hand account into the lives of young carers …………………………………………………………………...147

CHAPTER SIX

CHAPTER SEVEN

LIST OF TABLES

LIST OF FIGURES

INTRODUCTION

I. BACKGROUND

At a recent Global Peace Convention that drew more than 1,200 participants from 40 nations, the resounding take-away message was the challenge posed by globalization to the maintenance and sustenance of families (Lestary, 2013). Unpaid familial caregiving remains a crucial, but historically unrecognized component in the social reproduction of families, the term given to all those tasks involved in the daily and generational production and maintenance of persons (Bezanson & Luxton, 2006). Under capitalism, a reserve army of adult females, primarily wives and mothers, assume responsibility for the vast majority of social reproduction. Recent demographic, social, cultural, economic and political shifts triggered by more advanced global capitalism have reduced the number of hours this traditionally adult, female population has available to provide care for their family members. As a result, a growing number of children and youth have become a new reserve army of reproductive care labourers for certain sectors of the population.

This dissertation extends theories of social reproduction, as embedded in a feminist political economy framework, and highlights the connection between the growth in youth-based caregiving and changing social structures borne out of advanced global capitalism. Within an increasingly fragile economy, families' reliance on youth as a reserve army of reproductive labour, is evidence of deepening economic pressures on families. A growing number of families, including both single- and dual-earner families, and especially lower-income families with unmet care needs, are by necessity passing down the demands of familial caregiving onto youth who are seen as more flexible to accommodate certain facets of care. The emerging trend of unpaid caregiving amongst

Canadian youth reveals new and unanticipated challenges for families in their attempts to satisfy the growing demand for reproductive labour precipitated by broader demographic, political, socio-cultural and economic shifts.

At the demographic level, we are witnessing the first-ever reversal in the population pyramid structure wherein record declines in fertility exist against a rising silver tsunami of baby boomers. In 1950, less than 1% of the global population was over 80 years of age. By 2050, that share is expected to increase to nearly 10% across the OECD (Colombo, Llena-Nozal, Mercier & Tjadens, 2011). Improvements in life expectancy, and the shift from high-mortality/high-fertility society to low-mortality/low-fertility society has meant that an increasing number of persons are moving into old age with a decreasing number of persons at the bottom of the pyramid to support their reproductive care needs. Declining fertility and changing life course trajectories for women have also contributed to new and diverse family types. A growing number of families are childless, smaller, divorced and remarried, including stepchild-parents, LATers (individuals 'living apart together') and unmarried cohabitators (Mandell & Stamatopoulos, 2017).

Women's foray into paid employment over the past 50 years has also triggered necessary re-negotiations in the balance of unpaid reproductive care labour. To be sure, adult women remain the default persons for family care; however, the rise of dual-earner households under global capitalism has placed an unsustainable load on working women. As Hochschild & Machung's well-known study revealed to us, the 'second shifts' wage-earning women took on in order to satisfy the demands of both their paid labour outside the home and unpaid labour inside the home totaled an additional fifteen hours of work a week relative to men (1989, p. 259). In this context, additional family members, new technologies, community organizations and state-funded services were by necessity called upon to help balance the overwhelming family care and wage-earning demands placed on working women in an emerging globalized economy.

At the same time that socio-demographic shifts reduce the availability of women or other family members to engage full time in reproductive work, political-economic shifts, notably, the emergence of the neo-liberal state, increase the amount of social reproduction shouldered by individuals. The demise of the welfare state under globalization and the trend towards privatization of health and social care creates sharp distinctions between rich and poor households, especially those where one or more members suffer from a chronic illness, disability or mental health problem, in how the work of social reproduction is accomplished and by whom (Katz, 2001).

For those households unable to contract out care from non-familial sources, the options are limited. One option is for a family member, often a woman, to scale back on paid work which in the process contributes to the growing gap between the rich and the poor. When this option is not a financial viability, seeking out nontraditional familial sources to fill in the gaps becomes a secondary strategy. These two options available to families work in tandem to alter the generational structures of caregiving and support in unprecedented ways.

In 2012, over eight million Canadians aged 15 years or older were providing unpaid care to a chronically ill, disabled, or aging family member or friend (Sinha, 2012). Of these eight million and counting, the majority (60%) were juggling unpaid caregiving with paid work and childcare (Sinha, 2012) which resulted in care-related disruptions to paid work (43%) and a loss in some or all of work benefits, including extended health benefits, dental benefits, employer-provided pension, life insurance, and prescription drug plans (14%) (Sinha, 2012). The consequences of unpaid care for the many working and parenting adults helps to explain why almost 2.7 million Canadians aged 15 or older still cited an unmet or partially met care need in 2012 (Turcotte, 2012).

The challenge in providing long-term care for individuals is greater than ever before. It should come as no surprise that a growing body of research has arisen over the past two decades to spotlight the hidden lives of 'young carers' providing informal (unpaid) caregiving within their families.

As a result, this dissertation aims to correct for the gap in the Canadian caregiving literature by focusing on the unpaid care contributions provided by Canadian youth. Existing domestic caregiving literature focuses on the impact of caregiving on women and families, and in particular considers unpaid caregiving provided to older persons. This literature exposes the social-psychological and material consequences unpaid care can have on the adult women who take on the majority of these duties. From this research, we understand that race and class impact such reproductive labour trajectories, with the experiences of immigrant women working as elderly live-in caregivers or nannies confirming race and class-based care intersections (Ward-Griffin et al., 2005, Spitzer, 2004; Stewart et al., 2006). What we do not know much about are the experiences of young carers who provide substantial unpaid caregiving. First, however, we must define what we mean by term "young carer" and unpack the existing definitional ambiguity associated with the term.

II. MAPPING THE TERRAIN: WHO ARE YOUNG CARERS?

Young people, or 'young carers' include all those children and youth under the age of 25 years who provide *substantial* and ongoing unpaid caregiving to a family member or friend. Although no agreed upon numerical benchmark exists to identify what constitutes a 'substantial' caregiving load, experts have differentiated between those children (young carers) who are involved in *significant, substantial or regular unpaid care*[1], many of whom will take on these responsibilities at very early ages, and those children who, as part of their routine family lives and roles, may be involved in some aspects of caring but at a level which is neither substantial nor regular, and is not associated with unduly negative, damaging or restrictive outcomes (Becker, 2007, p. 26).

Replete in the literature is the apprehension around establishing what is considered a *substantial* degree of care. In the context of the United Kingdom (U.K.), official state definitions are purposefully vague in order to leave the onus on local authorities to determine what is considered "substantial" (Dearden & Becker, 1997, p. 134). Assigning numerical thresholds to what stands as a substantial or burdensome care level is further muddled by the subjectivity and differing individual appraisals of what counts as 'caregiving', versus simply helping out (Henderson & Forbat, in Chappell, 2011). As has been noted in the research on adult caregivers, differentiating between a 'labour of love' and 'unpaid work' has historically been an issue due to the failure of this labour to be recognized or valued (Luxton, 1980). Appreciating that all of these arguments hold merit and any such determination of care levels is open to negotiation, a framework for defining low, medium and high levels of care based on weekly hours of unpaid care and support provided per week is put forward. As discussed in Chapter Five, this youth-centered framework will account for the time the average teenager spends on various tasks on a given school day, arguing that certain caregiving thresholds present problems for youth as they affect the time required to satisfy their educational *and* familial demands.

Debates about what it means to be a young carer further extend to additional areas of the caregiving experience, including the young person's relationship with the care-receiver and the

---

[1] First defined by the UK Carers (Recognition and Services) Act of 1995 and co-opted by leading young carer experts, the ambiguous stipulation that caregivers provide "a substantial amount of care on a regular basis" (Section 101) was decidedly so in order to leave the duty on local authorities to determine what is considered "substantial" (Dearden & Becker, 1997, p. 134).

reasons behind the care provisioning. To date, most of the research focuses on all that intra-familial care provided in the context of long-term illness, disability or problems related to aging. Prototypical definitions out of the United Kingdom, the leading country on young carer research, focus on all that "care, assistance or support (provided) to another family member who is disabled, has some chronic illness, mental health problem or other condition connected with a need for care, support or supervision" (Becker, 2000, p. 378). Almost no attention is paid to extra-familial care and/or all that care provided outside of the context of chronic illness or disability. This dissertation thus calls for the widening of the young carer label to include all children and youth up the age of 25 years who provide both familial and non-familial care. In line with Charles, Stainton and Marshall (2011), this dissertation also agrees with expanding the list of eligible conditions propelling youth's caregiving to include parental absence stemming from either divorce, desertion or economic reasons compelling one or both parents to be away from home, as well as language difficulties that limit the parent's ability to communicate effectively with the dominant culture.

Further muddying the waters are those definitional ambiguities related to the age of the young carer. Official state-level legislation in the United Kingdom defines young carers as "children under 18" (Carers UK, 2014). In Australia, that figure is expanded to account for all those "young people under the age of 25" (Carers NSW, n.d). As it relates to the empirical research on young carers, a recent scoping review of U.S. caregiving scholarship reiterates this ambiguity. Kavanaugh, Stamatopoulos, Cohen & Zhang, (2015) highlight the operational variation related to the minimum and maximum age range of youth included in empirical samples of young carers. Of the 22 studies included in the scoping review, some studies include children as young as eight years of age, others include student samples on the basis of certain grade levels (e.g., grades 6-12) while others still categorize young carers as any individuals under the age of 18, 19 or even 21 years of age (Kavanaugh, Stamatopoulos, Cohen & Zhang, 2015). Outside of the United States, an even wider variation in these age cutoffs exist, with some including children as young as five years of age and young adults as old as 25 years of age (Becker, 2007).

Both conceptually and empirically, there are good reasons why older groups of youth should be included under the young carer label. These reasons take into account recent trends depicting the general lengthening of adolescence, often for those youth in middle to higher income families, across contemporary European and North American society (Larson, 2002). The period of adult life from the mid-twenties to mid-thirties, while previously acknowledged as the primary years for raising a family and building a career, is increasingly regarded as an extension of one's youth (Du Bois-Reymond, 1998). Compared to previous generations, young people today are in school longer, live with their parents longer and delay marriage and childbearing (Galarneau, Morissette & Usalcas, 2013). The growth of precarious and nonstandard labour prospects for younger workers further stalls successful pathway to adulthood. Compared to their parents, today's young people face an increasing wage gap between newly hired employees and more experienced employees, hold disproportionately more temporary jobs, and receive fewer positions covered by registered pension plans and union protection (Clark, 2007). For Stuart Tannock (2001), these early "McJobs" represent a particular type of "Stopgap job" – a job which exists largely outside of an institutional career path and is dominated by workers who have marginal labour market and job attachments (p.105). It is this stopgap youth culture that differentiates "youth" as opposed to "adult" workers and can continue well into their 30s (2001, p. 227). Accounting for these trends requires the widening of the young carer label to include all those younger persons up to the age of 25.

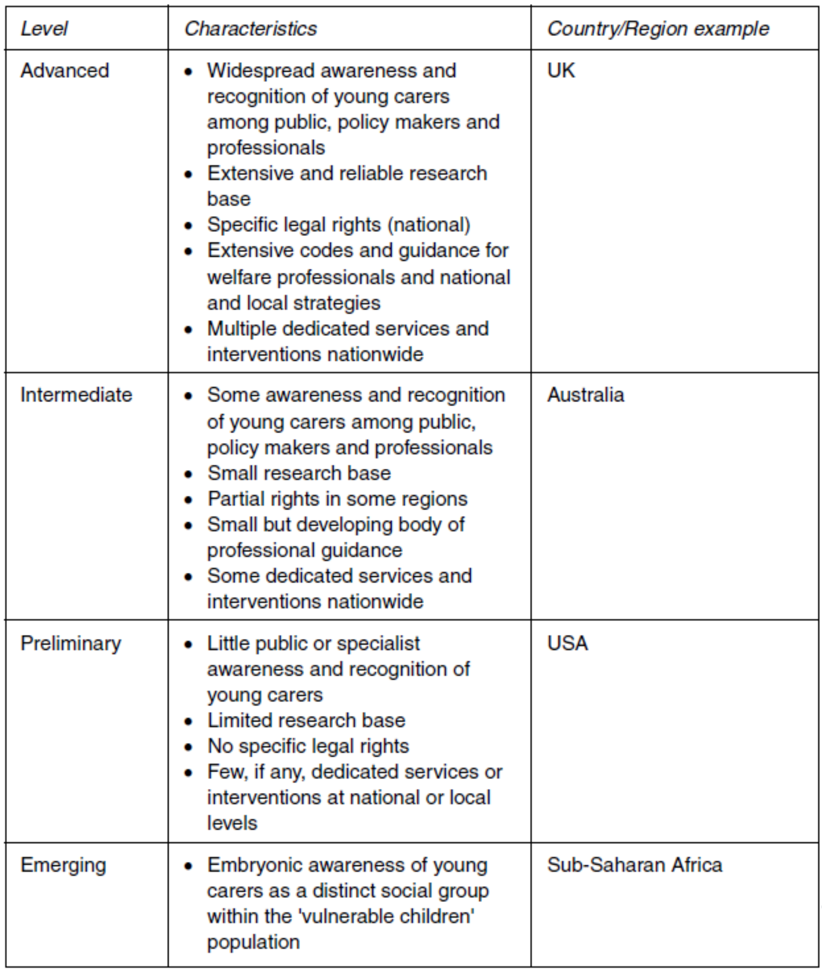
Finally, additional debates remain as to the appropriateness of classifying children and youth as a special interest group. Raised most ardently by those in the ‘disability rights’ camp, such critiques focus on the broader construction of children of disabled people as their “carers” (Olsen, 2000). Accordingly, the shifting of focus away from the disabled parent onto the children and youth in such families obfuscates the underlying problem of poverty and lack of support for many families which forces some disabled parents to solicit inappropriate assistance from their children (Keith & Morris, 1995; Olsen, 1996; Olsen & Parker, 1997). This dissertation supports claims from ‘disability rights’ scholars who note the connections between inappropriate or burdensome child-based caregiving, poverty and broader state-based policy. It also supports the calls made by young carer scholars (operating from a ‘children’s rights’ perspective) for the identification and support of children and youth as a distinct cohort of caregivers.

III. LOCATING CANADA WITHIN THE GLOBAL YOUNG CARER MOVEMENT

Most scholarship on young carers remains grounded in the United Kingdom, where the young carers movement originated and subsequently became entrenched in social policy. Following the United Kingdom’s lead, governments and scholars in other countries, mainly Australia, the United States, and Sub-Saharan Africa have taken an interest. In 2007, one the foremost experts in the field created a typology to characterize countries according to their national levels of young carer awareness and policy response (Becker, 2007). At that time, four countries occupied a position in the typology scaled from emergent to advanced (Figure I).

Sub-Saharan Africa held an *emerging* position characterized by an embryonic awareness of young carers as a distinct social group within the ‘vulnerable children’ population. The United States held a *preliminary* position marked by a larger (albeit limited) research base that coincides with a handful of dedicated local services. Australia held an *intermediate* placement marked by an even greater level of national awareness and recognition of young carers among the public, policy makers and professionals corresponding with partial legal rights and increasing young carer interventions (Becker, 2007, p. 42). The United Kingdom, however, was the only country to hold an *advanced* position due to its widespread awareness and recognition of young carers, extensive and reliable research base and legislative supports granting young carers a comprehensive range of dedicated services and programs (ibid). Canada did not make the list at that time.

Figure I: Becker's 2007 typology: Levels of awareness and response to young carers at the global level



Level	*Characteristics*	*Country/Region example*
Advanced	• Widespread awareness and recognition of young carers among public, policy makers and professionals • Extensive and reliable research base • Specific legal rights (national) • Extensive codes and guidance for welfare professionals and national and local strategies • Multiple dedicated services and interventions nationwide	UK
Intermediate	• Some awareness and recognition of young carers among public, policy makers and professionals • Small research base • Partial rights in some regions • Small but developing body of professional guidance • Some dedicated services and interventions nationwide	Australia
Preliminary	• Little public or specialist awareness and recognition of young carers • Limited research base • No specific legal rights • Few, if any, dedicated services or interventions at national or local levels	USA
Emerging	• Embryonic awareness of young carers as a distinct social group within the 'vulnerable children' population	Sub-Saharan Africa

Source: Becker, S. (2007). Global Perspectives on Children's Unpaid Caregiving in the Family. Global Social Policy, 7(1), 23-50.

Since 2007, a growing number of scholars and healthcare professionals have taken an interest in child and youth-based caregiving. Of the most advanced new entries include Norway, Sweden and Canada who together can be seen as occupying a 'preliminary' placement alongside the United States. Despite possessing a much less advanced domestic literature base compared to the United States, the strong push by Norwegian and Swedish policy and healthcare professionals to support "children as next of kin" has led to their official recognition in federal policy as of 2010 and 2007 respectively. These "children as next of kin" refer to all those children under the age of 18 years who have parents with severe physical illness and/or mental illness (PI and MI, respectively), and/or substance abuse (SA) (Kallander et al., 2017). Although no dedicated young carer programs exist in these countries, "next of kin" policies mandate that all healthcare professionals assisting adults receiving help for mental illnesses, drug addiction or severe physical illness or injury probe for the presence of children in the household. If children are present, then efforts must be made to ensure that such children receive appropriate information and follow-up, despite legislative ambiguity remaining as to what constitutes "information and follow-up" (Gullbra, Smith-Siversten, Rortveit, Anderssen & Hafting, 2014). Unlike the United States and Canada, however, the strong and long-standing concentration on children's behaviour and parenting ability has enabled these countries to institute state-based supports in the absence of a solid and pre-existing research base.

In the United States, the lack of political will to formally acknowledge and support young carers is tied to longstanding historical notions of individual responsibility and the model of neoliberalism that flows from it. Indeed, since the 2007 publication of Becker's global classification, the United States has remained stagnant given the persistent lack of legal rights and broader public awareness on the issue in addition to the lack of growth in dedicated young carer programming. The American Association of Caregiving Youth's (AACY) program continues to remain the sole program assisting such youth and its services remain localized to young carers living in Florida (Kavanaugh, Stamatopoulos, Cohen & Chang, 2015). The majority of the 1.3–1.4 million child caregivers aged 8 to 18 years across the United States continue to remain unsupported (National Alliance for Caregiving/United Hospital Fund, 2005).

In the decade since the publication of Becker's 2007 typology, Canada too has gained a 'preliminary' placement but for different reasons. Its literature base, albeit less developed than that of the United States, is greater than that of Norway and Sweden combined (Baago, 2004, 2005; Chalmers, 2011, 2012; Charles, 2011; Charles, Stainton & Marshall, 2008, 2009, 2010, 2012a, 2012b; MacSween & Maule, 2012; Nichols, Fam, Cook, Pearce, Elliot, Baago, Rockwood & Chow, 2013; Stamatopoulos 2015a; Stamatopoulos, 2015b; Toporas, 2003). It also possesses a handful of dedicated, albeit locally driven, young carer programs. The absence of legal or state-based rights afforded to such youth, and the persisting lack of broader national awareness of the issue prevents Canada and the United States from moving into a firm "intermediate placement". The lack of young carer programming as well as a more developed evidence base across Norway and Sweden similarly restricts their advancement to an 'intermediate' placement.

As a methodological note, the classification of countries using Becker's (2007) typology presents challenges when examining the case of Norway and Sweden. According to Becker's typology, a country can be classified as 'preliminary' if there are no specific legal rights in addition to a limited research base. An 'intermediate' placement, however, assumes the larger body of evidence amidst partial legal rights in some regions with the final 'advanced' category assuming a widespread awareness and recognition of young carers, an extensive and reliable research base and legal rights. Norway and Sweden find themselves straddling the eligibility of each of these three classifications with their limited evidence base, absence of dedicated young carer programming, and legislative healthcare rights for children of parental PI/MI/SA. These Nordic countries thus present a challenge to such classificatory schemes and highlight a complex and nonlinear path to the development of global young carer movements.

Irrespective of their differing levels of awareness and response to young carers, a rising number of individuals across a growing number of modern industrialized countries are taking an interest in child and youth-based caregiving. Thanks to their joint contribution, we learn that children and youth enter caregiving roles via two interconnected circumstances: (1) through individual and family decisions opting for informal care within the family, usually because other adult carers are not available within the kin network (e.g., in lone-parent families), and (2) through lack of appropriate, accessible and affordable formal service (Becker, 2007; Cass, Smyth, Hill, Blaxland & Hamilton 2009; National Alliance for Caregiving/United Hospital Fund, 2005).

A long list of social, educational, and health-related costs has also been documented resulting from the unduly burdensome or restrictive caregiving among children and youth. These range from increased sleeping difficulty, eating problems, trouble with the police, substance abuse and self-harm (Cree, 2003), to low self-esteem, headaches and increased bullying (Dearden & Becker, 2002a,b; Salter, 1999), depression, exhaustion and physical injury (Barber & Siskowski, 2008), and lower levels of educational completion and employment participation, and higher rates of school absences (Cass et al., 2009).

Positive benefits have also been noted to occur for young carers, including the development of practical life skills, an increased sense of pride and mastery as well as improved family relations (Clay, Connors, Day, Gkiza & Aldridge, 2016; Cassidy, Giles & McLaughlin, 2014; Joseph, Becker, Becker & Regal, 2009; Packenham & Bursnall, 2006; Packenham, Chiu, Bursnall, Cannon, 2007). Supporting youth in managing high levels of unpaid caregiving and its consequences thus becomes critical. Drawing attention to young carers in Canada, therefore, is of paramount importance for a number of reasons, the least of which is the contribution of Canadian-based research to the existing reserve of international young carer literature.

IV. CANADIAN YOUNG CARER LITERATURE

At the time of writing this dissertation, only five Canadian studies exist to provide a mix of qualitative and quantitative depictions of youth-based caregiving on a range of topics, including a discussion of the different levels of care provided and parental satisfaction of young carer program services. The earliest of these studies, conducted by the Multiple Sclerosis (MS) Society of Canada in 2002-2003, focused exclusively on the effects of parental MS on families. Using a two-stage design, the study involved a survey of parents and children (N=368) that probed the need for additional programs and supports for children with parental MS. Focus groups were also conducted with a convenience sample of children aged 6-12 (n=30) to explore the impacts of parental MS on their lives. The survey results "consistently show(ed) powerful impacts on the emotional and social development of children" with the highest levels of impact for the children's emotional development, participation in recreational activities, behaviour, and social activities with friends. School performance and physical activities are affected to a much lesser extent (Toporas, 2003, p.10). Children aged 12-18 reported that MS-related lifestyle limitations affected the entire family in all areas of life, especially having fun as a family. Moreover, these children were found to have substantially more responsibility in activities such as laundry, meal preparation, baby-sitting, personal and medical care for the person with MS, and in the management of the household compared to children without parental MS (Toporas 2003, p. 10). Results from the focus group indicated that children with parental MS experienced lifestyle limitations, emotional pain linked to lifestyle changes, the "emotional pain in seeing the daily struggle of their parent" and the uncertainty of their parents' future health (Toporas 2003, p.22). Increased worrying, guilt and anger were also noted among youth – linked to a variety of factors including the increasing burden of care provided to the parent, fear that the child may go through the same illness in adulthood, parental outbursts of anger or frustration triggered by the illness, and a loss of emotional support from the parents (Toporas, 2003, p. 22).

In 2010, a second study out of British Columbia (Charles, Stainton & Marshall, 2012a; 2010b) entailed a two-phase youth-targeted survey and retrospective immigrant-focused interview design. Phase One entailed the surveying of 483 youth aged 12 to 17 from a high school in a large urban centre in British Columbia about possible caregiving duties. Phase One findings indicated that 12.2% of high school youth reported being a young carer, with no statistically significant relationship between caring and one's gender, ethnicity or familial financial situation (Charles, Stainton & Marshall, 2010, p. 2). Phase Two involved conducting retrospective interviews with 50 adults aged 18 to 57 who lived in British Columbia and reported being a young carer at one point in their lives. Of the 50 participants, 20 (three males, seventeen females) self-identified as coming from immigrant families and it was those respondents who formed the basis of this sub-study. The participants varied in terms of occupation and socioeconomic status and were from families originating from a diverse set of countries including China, Germany, Holland, Hungary, India, Lebanon, the Philippines, Portugal, Russia, Serbia, Tanzania, and Vietnam. Phase Two findings probing the experiences of immigrant adults who were once young carers revealed several unifying themes related to: (1) a lack of recognition of the responsibilities the respondents had to play in their families as youth; (2) a premature maturity whereby caregiving youth were forced by their circumstances to grow up faster than would be expected; (3) increased isolation of youth from their peers due to their caregiving, and (4) the significant impact the caregiving had on them later in their lives, with many continuing to engage in caregiving roles as adults both within their families of origin and in other relationships (Charles, Stainton & Marshall, 2010a, p. 5). Positive impacts were also noted by participants and related to becoming stronger and more self-sufficient adults, increased appreciation of "the important things in life" and an increased sense of self-pride, maturity and sense of future familial duty (Charles, Stainton & Marshall, 2010a, p.88). Although the impact of gender was not discussed in depth, the authors did state that "participants had much in common, despite their many differences in gender, ethnicity, age, and circumstances" (Charles, Stainton & Marshall, 2010a, p.84). What remains to be known is how the experiences of this sub-sample of former immigrant young carers differs from the remaining 30 non-immigrant former young carers included in the wider sample.

The third study conducted by Chalmers (2011) involved a single-site quality assurance evaluation of the Niagara-based *Powerhouse Project: Young Carers Initiative,* a support program in Southern Ontario. Using feedback from parents of young carers in the program's two locations (one in the Niagara region, one in the Haldimand-Norforlk region), a total of 38 parent participants (representing 48 young carers aged 7 to 19) were interviewed by telephone between the months of March and April 2011. Additionally, a subsequent parent version of the Kärkkäinen, Räty, and Kasanen (2009) *resiliency* questionnaire was provided to participants for completion post-interview. Findings revealed that in both regional locations, parents cited being happy with the program and noted positive changes in their child after attending weekly programming (Chalmers 2011, p.8). Furthermore, parental assessment of the young carers' resilience (via the Kärkkäinen, Räty, & Kasanen scale) generally scored high, ranging from 28 (very low) to 75 (very high), with the majority scoring moderately resilient and above (Chalmers, 2011, p. 13). According to the report, overall findings suggest that caring during childhood and adolescence may not be as detrimental as previous research suggests, with the majority of interviewed parents (albeit, reporting on behalf of their children) indicating that their child's caring role helped develop them into mature, more responsible and understanding human beings.

The fourth study involved a sample of both U.S. and Canadian children of patients with Frontotemporal dementia (FTD); a neurodegenerative illness with early onset, before the age of 65 (Nichols et al., 2013). With funding from the Ontario Ministry of Health Alternative Funding Plan, the goal of this research was to learn more about children and youth's experiences living with parental FTD in order to assess what they needed at various points in the patient's diagnostic process and course of illness. Two skype-based focus groups were held with a total of 14 Canadian and American children aged 11 to 18 (10 female, 4 male) between the months of April and May 2011[2]. To be eligible for the focus groups, youth had to be: English-speaking, between the ages of 8 to 19 years and self-identify as a caregiver to someone with FTD. Thematic analysis of focus group data revealed seven overarching areas of interest, including emotional impact of living with a parent with FTD, caregiving, coping, symptoms of FTD, diagnosis, relationships and support. Some of the noted benefits of caregiving included youth's quick uptake of caregiving responsibilities, their failure to describe their added caregiving as a burden, and an expedited maturity and sense of priorities (Nichols et al., 2013). Some youth also stepped into a partnership role with the healthy parent in order to help share the burden of caregiving and household chores. Of the negative consequences noted, youth were shown to: (1) experience a range of negative emotions (e.g., anger, fear, embarrassment, guilt, confusion and frustration); (2) conceal their

---

[2] Delineation as to the breakdown of US-Canadian participants not provided by authors.

needs and fears for fear overwhelming the healthy parent; (3) experience gossip and rumors among peers at school, and (4) experience a form of "latent grief" resulting from the loss of the prior parent-child supportive relationship (Nichols et al., 2013, p.27). Finally, supports offered to youth in the study were largely restricted to those of an informal variety. The majority of participants acquired their primary support from the healthy parent and through talking with friends but did acknowledge the benefits of potential in-person support groups first and online forums second in order to connect with like youth. A disconnect was also noted between youth and healthcare professionals that was linked to the lack of involvement the child was afforded during the course of the diagnosis and treatments. Despite the challenges of caregiving, participants never described their caregiving as a burden, saw the experience of tending to a parent with FTD as generally a positive one, and gained a sense of expedited maturity and sense of priorities from their situations. The authors conclude the study by noting that successful interventions for young caregivers of FTD should incorporate the entire family and offer both educational and emotional support targeting the unique needs of the young carer.

The fifth and final study was conducted in 2012 in Edmonton and included semi-structured discussion groups with 11 employees, representing nine[3] non-profit community agencies in Edmonton (Waugh, Szafran, Duerksen, Torti, Grant & Shankar, 2015). Over a one-day group meeting held on January 20, 2012 from 8:00am to 3:30pm, researchers interviewed participants in order to gain a community agency perspective on issues related to young carers. Employees were asked about their encounters with potential young carers in their professional positons and if so,

---

[3] Alberta Caregivers Association (ACA); Alberta Alliance on Mental Illness and Mental Health (ALMIMH); Amyotrophic Lateral Sclerosis (ALS) Society of Alberta; Boys and Girls Club of Edmonton; Canadian Paraplegic Association (Alberta); CASA (Child, Adolescent and Family Mental Health) Child, Adolescent and Family Mental Health; Gateway Association for Community Living; Multiple Sclerosis (MS) Society of Canada (Edmonton); The Parkinson Society of Alberta.

what needs they presented. Analysis of written notes taken during the discussions revealed that while participants did not initially recognize young carers as a distinct client base, they subsequently acknowledged that such youth were indeed peripheral to their service programs (Waugh, Szafran, Duerksen, Torti, Grant & Shankar, 2015, p. 11). The lack of awareness and recognition among participants for 'young carers' and the 'young carer' label was also found to relate to the lack of community support programs for such youth. Considerable variation as to the definition of 'young carer' existed among participants, partly shown to relate to the ambiguity relating to what is considered caregiving compared to what is considered normal family caring responsibilities. Participants also expressed mixed support for the term 'young carer'. On the one hand, participants agreed that identifying and labeling young carers could result in positive changes linked to providing youth a "voice" to be heard and a platform towards recognizing and supporting their caring roles. On the other hand, participants also noted that labeling an individual as a young carer could have a negative impact by medicalizing the way the young carer or the care recipient view the caregiving relationship. Along these lines, if the care recipient does not identify or respect that they are in need of care, then what effect would this have on the individual identified as the young carer? Participants noted the importance of considering the effect that the terminology would have on the caregiving relationship. Finally, the authors conclude a major care gap exists for Edmonton's young carer population, with community organizations failing to allocate the necessary resources to provide targeted services aimed at addressing young carers' unique needs.

Taking into account that only three of the above studies provide first-hand accounts of youth-based caregiving via survey data (Charles, Stainton & Marshall, 2010) and focus group data (Toporas, 2005; Nichols et al., 2013), it is clear that additional research must be undertaken to capture a wider range of caregiving youth across a variety of geographical and socio-cultural contexts. Furthermore, no information exists on the incidence of young caring across Canada nor the range of Canadian programs currently available to support youth in such caregiving roles. This dissertation will fill in some of these existing gaps in the literature by answering more targeted research questions aimed to elucidate our understanding of youth's contributions to unpaid caregiving, their experiences with caregiving and the supports available at their disposal.

V. PURPOSE AND RESEARCH GOALS

In 2013, an Action Canada Task Force was undertaken to raise awareness for the 'invisible population' of Canadian young carers. The team of Canada-wide researchers concluded that not only is it necessary to raise awareness for young carers across Canada but also that efforts at data collection, research and help-based services be improved and expanded. Despite the recommendations of the task force, political and policy platforms have remained silent on the issue, with only a small group of researchers and social workers contributing home-grown empirical research to the existing global literature.

This dissertation is thus comprised of four overriding research goals that seek to elucidate our understanding of children's contributions to unpaid caregiving specifically and what it means sociologically. First, a feminist political economy framework will be used to locate the phenomenon of child and youth-based caregiving within the context of larger societal change triggered by advanced global capitalism. This type of approach moves beyond merely focusing on the micro, family-level circumstances requiring such youth-based caregiving (i.e., familial illness or disability) and seeks to understand the macroeconomic conditions that facilitate a shift in the balance of reproductive labour provisioning. Within the existing reserve of young carer literature, the linkages between wider macro-structural change and increased child and youth-based caregiving remain largely absent and the wider de-contextualization of young carers from the society in which they belong has prevented a clearer explanation as to why the phenomenon has increased over recent decades and in certain locales. Second, a statistical trend analysis of youth-based caregiving will be provided using available national datasets in order to better understand the incidence and nature of youth-based caregiving across Canada. Third, a first-person account of the experiences of caregiving from the perspective of Canadian youth will be provided via group interviews with a sample of Southern Ontarian youth. Fourth, the current state of young carer policy and programming available to young carers will be reviewed while pinpointing the structural conditions working against their expansion.

Ultimately, the goal of this research is to help raise awareness for young carers across Canada and provide the additional evidence required to secure the rights and supports they so urgently need.

VI. ORGANIZATION OF THE DISSERTATION

In the first two chapters, a review of those sociological theories of care and childhood that best ground the phenomenon of youth-based caregiving will be put forward, focusing not only on the structural conditions contributing to its rise but on the social forces propelling the more recent revaluation of children's usefulness in modern Western Civilization. By addressing how previously normative conceptions of childhood and children's work are under reformation due to broader structural shifts borne out of advanced global capitalism, this dissertation adds a unique sociological analysis to the rise of youth-based caregiving that is missing from the more traditional young carer research base. Notwithstanding the empirical focus on youth aged 15 to 25 (quantitative analysis) and 15 to 19 (qualitative analysis) in this dissertation, discourses of youth are predominantly grounded in historical narratives that demonstrate changing conceptions of *childhood*. This is a necessary consequence of the term "youth" being a relatively recent invention of the early to mid-20th century. As it will be shown, the birth of the term "youth" or "adolescent" to refer to post-pubescent children, is an offshoot of the larger childhood label, with the latter borne out of the former and both borne out of changes ushered in by industrialization.

Chapter Three turns to a discussion of the multimethod research design chosen for this dissertation and the considerations guiding the choice of quantitative (statistical) and qualitative (interview, focus group) design and analysis. Discussion will be given to the limitations of the secondary data sources, the challenges in sampling young people more generally and young carers specifically, and what is needed going forward to improve forthcoming data collection. Lastly, a personal reflection on both my experiences in the field and the efforts taken to ensure the methodological and analytical quality of my data and subsequent results is offered.

Chapter Four presents the results of the quantitative portion of the dissertation. In this chapter, the goal is to provide the first known trend analysis of youth-based caregiving in Canada using census data for the 1996–2006 time-period. Added detail unavailable from the census is supplemented by way of the 26th cycle of the General Social Survey on "Caregiving and Care Receiving". Together, these two datasets will produce national prevalence estimates and growth rates, highlight the socio-demographic characteristics of caregivers and their care receivers while also exploring the role gender has in both the level and types of care provided.

In Chapter Five, focus will be drawn to the qualitative interviews conducted with young carers themselves, adding a glimpse of the youth experience of the adult-centric care literature. Using a qualitative approach (i.e., focus group and individual interview data), the experiences of a sample of 15 young carers from the Niagara Region and Greater Toronto Area within Southern

Ontario will reveal the benefits and challenges of caregiving for youth. The complex and often contradictory nature of youth-based caregiving will demonstrate that despite their remarkable resilience, young carers incur a palpable and largely overlooked and unsupported ‘young carer penalty’ that compromises their current and future well-being and development.

Chapter six rounds out the empirical research by providing the first known qualitative review of existing young carer programs in Canada. First, a review of the current landscape of young carer policy and programming across Canada will be presented, accounting for the origins of the budding movement and contrasting it with the U.K., the most advanced nation for young carer awareness, social policy and service provisioning. Next, the results of qualitative interview data with frontline staff at each of the three existing Canadian young carer programs will reveal both the range of services available to young carers but also the barriers to improving their scope and reach.

In Chapter Seven, the dissertation will be brought to a close by summarizing the key findings of the research while highlighting its strengths and limitations. Also, a three-pronged recommendation strategy will be offered for follow-up research, policy and programming for Canadian young carers.

CHAPTER ONE

Childhood in Modern Western Civilization: The Re-Emergence of the Reproductively Useful Child.

1.1 INTRODUCTION

While experts in a handful of regions (i.e., United Kingdom, Australia and Sub-Saharan Africa) have amassed a solid base of empirical research on youth-based caregiving over the past two decades, its roots in social work, nursing and psychology predominantly offer pathological, individual-level accounts. This dissertation seeks to correct this bias by providing a macro-level sociological explanation for both its recent rise and the growing attention youth-based caregiving has received across an increasing number of countries.

By grounding the phenomenon of unpaid caregiving among children and youth within a broader moment of change unfolding in the lives of Western industrialized children, this analysis will reveal how youth-based caregiving not only challenges previously held notions of childhood but also signals its growing incompatibility with modern-day global capitalist society. In the context of globalization and neoliberalism, the traditional family has come increasingly under attack. More and more families are forced to rely on the help of their children to fill the unpaid work shortages previously fulfilled by the adult women in their households (i.e., their mothers). Due to a range of factors, including rising female labour market participation (which is accompanied by a corresponding loss in the full-time reproductive labour performed by adult women), changing family types (e.g., the rise of divorce, lone-parent and multigenerational families) and an ageing population amidst welfare state retrenchment, the need for caregivers has grown exponentially over the past 30 years. For such families, there has been a shift from children and youth merely "helping out" casually or occasionally to becoming important and useful contributors to their family's welfare and thus occupying a new realm of importance within the reproductive, unpaid economy.

Acknowledging the disagreement among academics as to the reasons for the changing roles of children in contemporary capitalist society, this analysis falls in line with Qvortrup (1993, 1999, 2001) who links changing conditions of childhood with shifts in parental work situations. Taking a materialist approach, Qvortrup’s focus is on the changing mode of production from pre-industrial (agrarian) to industrial society and the parallel between children becoming less useful for their parents, their subsequent movement into compulsory education, and the emerging industrialization and urbanization. As he puts it:

> What happened was that children as a collectivity changed their main mode of activity in accordance with the major change in the dominant mode of producing; it was not a change due to a new discourse among educationalists or child savers, but it was a change that was demanded of a new industrial system, which was in need of a mobile, educated labour force (Qvortrup, 1999, p. 12).

Qvortrup suggests that once the fundamental economic structure of society changes, so too do socio-cultural and demographic patterns. My analysis extends Qvortrup’s work by focusing on how more recent structures borne out of global predatory capitalism over the past three decades alters the social reproductive work of children and youth by first changing the work lives of their parents, especially mothers. Unlike materialist approaches to economic restructuring that deal with the gender-neutral ‘undifferentiated man’, this analysis employs a feminist political economy orientation. To this end, this analysis sees economics as an extension of politics and relations of power as they influence the production, distribution and consumption of goods and services. It also accounts for the (political) management of these economic variables, relationships and functions (i.e., “political economy”) and highlights how gender determines or influences those social and political relationships and structures of power, and the differential economic effects that flow from these relationships and structures (Murphy, 2004). Changing socio-economic conditions for women within Western industrialized societies, particularly women’s changing paid employment patterns and demands for both productive and reproductive equality, operate in tandem to effect change for previously dominant constructions of childhood.

Social reproduction feminism or SRF – a strain of feminist political economy – provides a vehicle for understanding how recent rises in child and youth-based familial caregiving result from such macro level economic change. Complementing strict materialist or Marxist feminist perspectives that focus primarily on the formal/productive labour market, SRF incorporates both the value producing labour associated with the waged economy, and the domestic labour (typically performed by women) required to give birth to, feed and raise the current and future generation of workers (Ferguson, 2008).

Exploring how women’s added representation in the paid/productive economy in advanced global capitalism creates new tensions with their historical responsibility in the unpaid/reproductive labour market provides a clearer understanding of the increasing reliance on children and youth for the uptake of some of the residual reproductive care gaps. Children and youths’ changing involvement in the paid and unpaid economy demonstrates how such labour trajectories ebb and flow alongside broader macro-level changes linked to the under-riding economic structure of society. Demonstrating the historically malleable and socially constructed nature of “childhood” more generally and “child labour” more specifically adds further weight to the precariousness of its supporting ideology.

Taken together, this analysis argues that the result of changes ushered in by global capitalism is the necessary revaluation of that which is deemed acceptable, if not necessary, unpaid labour among children and youth. A SRF perspective reveals how structures borne out of advanced global capitalism call forth certain actions and behaviours among children and youth, mainly in terms of the expansion of the reproductive labour they provide within their families. Not applicable to all children universally, this expanding definition of necessary unpaid reproductive labour will be shown to impact certain groups of youth more than others. Children in dual-earner, single-parent or multigenerational households with chronic illness, disability or problems related to aging will be more likely to be called upon as reproductive labourers. Children in low-income families which cannot afford to contract out unmet reproductive care needs will also be disproportionately affected compared to wealthier families. The rising number of young carers across Canada and other Western advanced industrial societies can therefore be understood as but one increasingly viable strategy for families struggling to satisfy unmet care needs provoked by the wider institutional, economic, and cultural destabilization activated by global capitalism. The once pervasive and popularized discourse of a labour-free childhood in modern Western civilization, certainly as operating over the past 150 years, has been called into question.

As a necessary point of clarification, when discussing children's *labour* in the context of this dissertation, reference is not being made to "child labour" as discussed by the international movement spearheaded by groups such as UNICEF, the International Labour Organization (ILO) and various non-governmental organizations (NGOs) over the past 40 years to ban the dangerous and highly exploitative paid work of children in the global south (Bachman, 2000). I am also not referring to the largely "unchartered economic worlds of children" in both the global north and south that childhood scholars have discussed, particularly as it involves their extensive and consequential involvement with the varied production, distribution, and consumption processes (Zelizer, 2002, p.3). Instead, reference is made to the unpaid, reproductive care labour children and youth provide within their families in the global north and in advanced global capitalist societies.

As a secondary point of clarification, the use of the word "child/childhood" in historical discussions surrounding changing discourses typically covers the experiences of both child and youth populations. While this practice is reductionist, it is a necessary consequence of three factors. First, the "Child Study Movement" that first emerged in the late 19th century and early 20th century, which represented the first scholarly and political campaign to differentiate children from adults, began as an essentialist one. The ontological claim that the generational cohort of children aged 0 – 18 "must be viewed in their fullness as human beings and as a generational and social class in all its civic, political, social, economic and cultural dimensions" kept both child and youth populations an amalgamated group (Kraus, 2015, p. 16). Moreover, noted historical studies analyzing changing conceptions of children and childhood (e.g., Aries, Zelizer) rely on archival evidence that similarly fails to differentiate between the two sub-populations. Only when there is a clear demarcation between the two will the term youth or adolescents be employed in corresponding historical discussions.

Second, it is only with the progression of the industrial revolution and the en masse shift from rural to urban living, did the host of social problems linked to post-pubescent children gain wider attention (Hartinger-Saunders, 2008). It is in this landscape that G. Stanley Hall (1904) would first coin the term "adolescents" to explain the period of "storm and stress" that occurs among post-pubescent children. It is also around this time that the Chicago School of Sociology would begin its now famous ethnographic research endeavor exposing the rising "juvenile" problem among economically and ethnically marginalized youth in emerging industrial metropolises (Hodkinson & Deicke, 2007). Subsequently, the creation of conceptually distinct definitions and research agendas for this new subpopulation of older children (i.e., youth, adolescents) arose to reflect stalled pathways to adulthood for teenage children who, a century prior, would have already transitioned into marriage and full-time labour. Blocked pathways to adulthood and the "trouble" that arose when older children were rejected from the workforce and left unsupervised for long periods of time became an emerging theme of research in the early 20th century (Regoli & Hewitt in Hartinger-Saunders, 2008).

Third, more recent shifts triggered by advanced global capitalism have worked to "de-differentiate" the life-course boundaries not only of children and youth but of youth and adults as well (Featherstone & Hepworth in Hodkinson & Deicke, 2007). Pursuant to this, postmodern theorists highlight how fixed definitions of previously defined age cohorts (e.g., childhood, youth) have begun to erode under an era of perpetual youth and the blurring of life course boundaries. As a result, life course stages are less constrained by age as a form of social stratification and as a result, many have argued that an increasing difficulty has arisen in stipulating where childhood ends and adolescence begins and whether age norms still hold (Hunt, 2010). It is precisely for these reasons that children and youth are referred to together under the figurative label of "children" for the corresponding historical discussions surrounding changing experiences.

1.2 SOCIAL REPRODUCTION FEMINISM (SRF): A GUIDING FRAMEWORK

SRF is especially useful to appreciate the changes brought on by globalization. Given that dominant discourses on globalization have long been presented as gender (and race) neutral, the implicit "masculinization of these macro-structural models" has assumed an unlimited supply of unpaid caring, household, and all that remaining informal economic labour that maintains human life (Freeman in Acker, 2004, p. 3). The assumption that the vast majority of unpaid reproductive labour provided by women was a fixed commodity prevented the foreshadowing of what can happen when that assumption is called into question. The important differences between the realities of women's and men's lives under globalization, and how these gendered experiences subsequently trickle down to influence the experiences of youth, are only fruitfully revealed when accounting for such gendered forces. By 'gendering' such discourses, SRF exposes the breaks between the realities of men's and women's lives and produces a better understanding of understanding of contemporary global issues (Acker, 2004).

Embedded in feminist political economy, SRF provides an understanding of how various institutions, such as the state, market and family, interact and balance power to assure the daily and generational production and maintenance of people is completed (Bezanson & Luxton, 2006). Although social reproduction involves both paid and unpaid processes used to maintain and reproduce the population, this analysis pays greater attention to the more common unpaid and informal support provided by individuals, with little or no training, that is based on an existing relationship (Armstrong & Kits, 2001). The demarcation between productive and reproductive labour is thus central to this analysis. The former refers to the paid, wage labour that goes into the production and distribution of goods and services contrasted with the latter which reproduces future labour and/or maintains the existing productive labour force (e.g., cooking, cleaning, washing, feeding, and all those care tasks typically identified with a mother). Traditionally, social reproduction is carried out for free, within the home and predominantly by adult women and is viewed as a "labour of love" geared towards the advancement of the family unit as a whole. Gendered divisions of labour are supported by powerful ideological constructs that differentiate between female and male, feminine and masculine and ascribe biological rationales for such differences (Luxton, 1980). These "ideologies of familialism" historically revolve around women and men being viewed as "naturally" hard-wired to provide different types of labour: women should marry and have children and assume primary responsibility for child care while men are to assume primary responsibility for earning the money needed to support the family (Luxton, 1991; Luxton & Fox, 2009).

Social reproduction theorists have been crucial in showing how more recent neoliberal-inspired state and economic restructuring has involved an offloading of reproductive care labour onto families and communities. Specifically, when reproductive labour is de-institutionalized, it is women who bear the primary responsibility for its uptake. This occurs as women take on such labour for free, working double and sometimes triple shifts to provide care to children and older persons when gaps in affordable and accessible care options emerge (Cranford, Vosko & Zukewich, 2003; Hochschild & Machung, 1989; Noack & Cosko, 2011; Vosko, 2006). This also occurs in the paid labour market, where newly downsized and once well-paid public-sector care labour becomes the domain of the less secure and poorly paid private care market (Armstrong in Ginden et al., 2005; Gibson, O'Donnell & Rideout, 2007; Pupo & Thomas 2010).

Importantly, SRF helps us understand how that which is considered socially acceptable and necessary care work varies culturally and historically and reflects the balance of gender, class, and race/ethnic power relations (Bezanson & Luxton, 2006). The intersection of class, race and gender is most evident when women from the global south come to Canada to work as nannies and live-in caregivers. The *transnational mothering* (Arat-Koc, 2006) they provide reveals how the work undertaken by this female migrant labour force is undervalued, in that it is poorly paid and done by women who often have little access to citizenship rights and are subject to surveillance and control (Bezanson & Luxton, 2006, p. 8). Although social reproduction theorists have comprehensively accounted for how women’s situations and their relationship to the economy are intimately connected, much less is known about how children and youth’s situations are similarly connected to the economy.

By inserting the child into SRF, this dissertation aims to contribute to existing literature by illustrating how young carers represent a necessary byproduct for many households that require supplementary care to manage the full-time, stay–at–home care once provided predominately by adult women who have historically been the default person for family care (Mandell & Stamatopoulos, 2017). The replacement of the male breadwinner–female caregiver model with a dual–earner female caregiver model has placed an unsustainable burden on adult women to manage the demands of both paid labour outside of the home and unpaid labour inside the household. Resulting re-negotiations in the distribution of social reproductive labour performed across the state–market–family/household–third sector nexus is a direct response to managing the tensions between social reproduction and capital accumulation (Bezanson & Luxton, 2006).

Such tensions spur on debates and questions surrounding how families and society should be organized. For example, is there a social responsibility to care for family members or is it a private problem? Is care for children and older adults a set of tasks all members of a household should participate in or is it solely the responsibility of a few? The answers to these questions have disproportionately involved changes to women’s lives. True, married men have begun to take on a greater share of *housework* across Canada but their rate of participation for other reproductive labour tasks (i.e., primary child care and shopping for goods and services) has remained stable over the past 20 years (Marshall, 2006). What is less well documented is how children and youth have been drawn into such debates and questions during such periods of challenge and change.

Indeed, the rising number of young carers across Canada and other Western advanced industrial societies can be understood in terms of their power as an increasingly viable reserve army of reproductive labourers.

Reviewing historical variations in children's productive and reproductive usefulness adds further weight to this claim by demonstrating how normative conceptions surrounding child labour have undergone parallel debates, negotiations and ideological alterations. The socio-historical specificity of childhood has raised questions for children. What role should children and youth have in their family labour unit? Do class, race and gender intersect to impact the reproductive labour of children and youth? Answering these questions involves exploring how children's so-called usefulness has varied over time in accordance with periods of social and economic change. This involves taking one of two main approaches in the area of childhood studies: the first one deals with 'childhood' as a social form that changes in accordance with key societal macrostructures (a structural approach) while the second one deals with 'children' as agents and participants in society (an agency approach) (Corsair, 1997).

To clarify, when speaking of the social constructionist nature of "children" and "childhoods" we are referring to the historical specificity of meanings and values attributed to childhood and its transformation over time owing to economic, demographic, technological and socio-cultural forces. Thus, although we have grown accustomed to viewing children in Western advanced capitalist society as precious and developing beings who require a differentiated life course comprised predominantly of formal education, social play and very limited (informal and formal) labour to ensure their 'proper' psychosocial development, this ideology has not always been the norm. Contemporary ideas of childhood and children's role in the family economy represent a historically recent phenomenon of the past 150-200 years. Young carers as a collective represent a break in the precious and non-labouring childhood that reigned supreme over the past two centuries and signal its ongoing re-evaluation in response to advanced global capitalism. To be sure, the lives of adults have also undergone separate ideological re-evaluations during this period. For the purposes of this analysis however, a structural approach will be used to demonstrate how and why changing conceptions of children, as a separate non-adult demographic, have shifted in accordance with such macrostructural social change.

1.3 CHILDREN'S HISTORICALLY CHANGING USE VALUE

In his 1962 book entitled *Centuries of Childhood* (considered one of two foundational books in the field of childhood and children's history)**,** Phillippe Aries was the first to lay the groundwork for a constructionist framework of childhood. Using extensive archival analysis of a wide range of medieval writings and artwork, Aries documented how the family changed from an institution created out of economic necessity based on the practical exchange of skills and contribution, with little or no emotional content, to its modern model organized around meeting the emotional needs (i.e., of love and affection) of its members, especially children. For Aries, a great demographic revolution occurred in the West from the 18th to 20th centuries which revealed considerable possibilities of change in the structures of the "family" and "childhood" hitherto believed to be biological and invariable (Aries, 1962). Rather than seeing 'the family' as weakened with the advance of liberal individualism, Aries argued with industrialism or modernity, the family gained a new place in society, "perhaps never before exercising as much influence over the human condition" (Aries, 1962, p. 10).

According to Aries, the 21st century concept of childhood was nonexistent in the medieval period. It grew into existence among the upper classes in the 16th and 17th centuries before mushrooming among the lower classes by the 20th century. As Aries shows us, life was lived in the public prior to the 16th century, with children mixing with adults as soon as they were considered capable of doing so without their mothers or nannies, typically not long after the age of seven.

The typical childhood trajectory involved the child leaving home (even if returning to it later) to become a domestic servant or apprentice in another family's household where the "transmission from one generation to the next was ensured by the everyday participation of children in adult life" (Aries, 1962, p. 368). In this way of life, Aries concluded, profound existential attitudes between parents and children were prevented, with children and the family constituting a practical reality rather than a sentimental one. Parents cared for their children but they "cared about them less for themselves, for the affection they felt for them, than for the contribution those children could make to the common task" (Aries, 1962, p. 368). Reflecting the largely instrumental versus emotional valuation of children was the commonplace custom of burying non-baptized children on the threshold or in the garden "much as we today bury a domestic pet, a cat or a dog" (Aries, 1962, p. 39).

Although Aries' views of medieval life are criticized as idealized and simplistic representations, there seems to be a general agreement that while some aspects of childhood remain invariable, others can and have changed, and rather significantly. Children's role in productive and reproductive labour is one such aspect. Helping to clarify how changing economic structures impact children's usefulness, Historian Peter Stearns (2010, 2016) expands on Aries' binary pre-modern/post-modern classification by looking at how the first transition from hunting and gathering economies to agricultural economies invoked changes just as dramatic to childhood as those facilitated in the shift from agricultural to urban, industrial economies.

In the nomadic hunting and gathering societies, families were often smaller in size, given the difficulty in carrying small children from one location to another. Children would help their mothers in the gathering of seeds, nuts and berries; however, their needs regularly outstripped what they could contribute (Stearns, 2010). In such societies, children often held little economic value in life until they were in their teens. The limitations of children's utility shaped the conception of childhood in key ways. Representations of children in primitive art were few and far between. Deliberate infanticide and induced abortion via experimentation with plants was commonplace. Childhood was also shortened with girls and boys introduced into marriage and adulthood in their early teens. This posturing toward children helps to make sense of the practice of foregoing the burial of children passing before the age of five in such societies (Stearns, 2010).

With the move to an agricultural economic system some 10,000 years later, major changes in ideas regarding the utility of children emerged out of the changing structure of the economy. The centrality of work marked a core definition in childhood that deserves special attention. In agricultural civilizations, which lasted up to 1750 before drawing to a close (Stearns, 2017), children's labour was used extensively to supplement adult labour in farming and craft manufacture. Useful work became the core definition of childhood in most agricultural classes – including those devoted to craft production and home manufacturing (Stearns, 2010, p. 20). Although it is not known how quickly agricultural families realized that children provided such an essential labour force, birth rates began to rise fairly rapidly and a sharp break between infancy and early childhood led to "serious work" beginning for children as early as six or seven (Stearns, 2010, p. 22). Variations in boys' and girls' labour existed but only in a general sense. Young children helped their mothers at home; slightly older children tended to domesticated animals and assisted with work in the fields and adolescent boys hunted. Whatever the variation, the key point was that regular work activity was a core definition of childhood in most agricultural classes (Hindman, 2009, Stearns, 2010, 2017).

Unlike hunting and gathering societies that were eager to truncate the period of childhood, prolonging childhood became an important mechanism in the social reproduction of agricultural families. Marriages were postponed until children were in their late 20s in order to extend their involvement in the family labour team. When delaying adulthood was no longer an option, couples were known to conceive again in their early 40s to have a "wished child" (or Wunschkind in German) who could continue to work for them if they reached old age (Stearns, 2010, p. 22). Despite children's new and important roles in the family labour team, high death rates (up to 30-50% of all children perished before the age of two in agricultural societies) continued to prevent greater emotional attachments being formed for children during this era.

For Stearns, four major changes separate modern childhood from childhood in agricultural society. First, the conversion of childhood from work to school gave way to the notion that children should not work at all in favour of academic development, leading to a shift in normative views of children as economic liabilities instead of assets. Second, unprecedented declines in fertility suggest that families actively took actions to limit fertility. The previous average of five-to seven children per agricultural family was now inappropriate for conditions in which the costs of raising children outstripped their potential economic return. Third, declining fertility, amidst dramatic reductions in infant mortality, encouraged more concern about saving children who were born. Fourth, the nation state took an increasing role in protecting and monitoring the development of children in the modern, industrial era. Where families once held the primary responsibility for children, the state now intervened to monitor children's development. Mandatory schooling and child labour laws preventing employment in the paid labour market and laws granting the seizure of children from negligent parents are all examples of the new role of the state in monitoring childhood. Together, these changes led to an increasing idealization of children in the West and their gradual removal from the family labour team from the mid to late 1700s and onward.

In what is considered the second foundational text in the field, *Pricing the Priceless Child* (1985), Viviana Zelizer reveals the profound transformation in the social, cultural, emotional, and moral value of children in the United States from the late 1800s to the 1930s. By analyzing a wide range of historical data, Zelizer's work demonstrates how children instantiated certain kinds of social value in the late 19th century that gave cultural meaning and historical specificity to their parents' affections and led to the development of institutions that reflected those new meanings. The rise of the economically "useless" and emotionally "priceless" child signified a momentous shift in the ideology of childhood. Priceless children did not undertake paid labour.

By detailing how new institutions (i.e., children's insurance, compensation for the wrongful death of children, and the adoption and sale of children) were involved with the economic and sentimental valuation of child life, Zelizer demonstrates how the changing meanings and value of children resulted in a "sacrilization"[4] of child life that drastically altered the life course trajectories of most children in Western capitalist nations, particularly working-class children.

The first of these institutions to reflect children's new sentimental value was that of *children's insurance*. Contrasted with a time not too long before when the bodies of these "little strangers" were simply "sewn into shrouds made of cheap sacking and thrown into big common graves" (Zelizer, 1985, p.25), parents now became desperate to provide proper burials for their new priceless angels. To illustrate, John F. Dryden of Prudential Life began selling life insurance to parents for their children aged 10 and under at an affordable weekly rate between $0.05 to $0.10

---

[4] A term she gives to the process whereby adults invest children, and childhood, with sentimental or religious meaning (Zelizer, 1985, p. 21).

cents in 1875; by 1895, they had insured over 1.5 million U.S. children at a total cost of $268 million (Zelizer, 1985, p. 116). The class-wide rise in child mourning made the act of insuring one's children a "semi-ritualistic business" that symbolically represented parents' love and concern for their children (Zelizer, 1985, p. 137).

The second institution to shift in accordance with the new emotionally priceless value of children was that of the courts, with the *legal evaluation of children* undergoing a co-attendant change. Where once children's surrender value (i.e., the amount payable to a person who surrenders a life insurance policy) was calculated strictly by determining the value of lost labour and services of a young child, doing so in the new cultural era of the priceless child was deemed crass and demoralizing. A stark contrast of the new valuation of children can be seen when comparing the case of a Georgia family who sued a railway company in 1896 for the wrongful death of their son and the case of an Arizona family whose infant son accidently contracted HIV through a blood transfusion in 1991. In the 1896 case, no judgment was awarded to the family given the child was "of such tender years as to be unable to have any earning capacity" (Zelizer, 1985, p. 138). In the 1991 case, the parents were awarded $28.7 million in damages. Paradoxically, only as children became economically useless did their surrender value climb sharply and a form of "sentimentalized economics" emerge (Zelizer, 1985, p.158). Now, judgments in wrongful child death cases (i.e., "death money") became different from ordinary cash, they too became sacrilized. The escalating size of the awards revealed how they became imbued with what George Simmel called a "super-additum" that reflected the new sentimental determination of a child's economic price (Simmel in Zelizer, 1985, p.163).

Finally, practices surrounding the *sale and adoption of children* came to reflect the changing value of children. Virtually no market existed for babies in the 1870s; legal adoption was rare and the only thriving market was one dedicated to getting rid of unwanted babies via "baby farmers" who would board unwanted and usually illegitimate children for about $10 a month (Zelizer, 1985, p. 170). By the 1950s, however, parents were paying upwards of $10,000 for the adoption of an infant girl. Interestingly, older children, especially boys, were virtually unable to find homes in the new adoption markets compared to little girls. This stands in stark contrast to the pre-modern valorization of older boys for their greater productive capabilities. It was young girls who commanded a higher sentimental value with the new emotionally priceless, economically useless industrial model of childhood.

Zelizer's focus on children's changing usefulness highlights the socio-historical specificity of what was deemed valid and socially acceptable child labour from the mid-to-late 1800s to the early 1900s. Previously, children were employed in a wide variety of adult forms of productive labour with the value of children assessed largely in terms of their productive power. Elder male children yielded a higher earning power to their families than did their female siblings given the wider range of socially acceptable farming and industrial labour they could provide. Boys were more valuable to their families. Reflective of this worth were those accidental (court) death judgments that relied solely on economic guidelines to estimate the cash equivalent of lost labour and services for a passing child. The "surrender" value was almost always higher for older children, particularly older boys, who fetched the highest premiums and were the most likely to be employed in the emerging industrial sector (Zelizer, 1985, p.15, 139). Of the kinds of productive labour in which children were engaged, very little was deemed unacceptable. Prior to the 1870s, children's labour was a mere reflection of adult labour. Indeed, the "small and nimble fingers of little children were by very far the most in request "to manipulate the emerging machinery of early industrialism" (Marx, 1887, p. 783). According to U.S. statistics, children accounted for over 20% of manufacturing employment in the American Northeast by 1820 (Goldin & Sokoloff, 1982).

The Canadian context followed a similar trajectory to that documented by Zelizer in the United States. Canadian and non-Canadian children's labour was integral to the success of early industrialism. As early as 1882, a federal *Report of the Commissioners Appointed to Enquire into the Working of Mills and Factories* documented the widespread involvement of children in the factory and in the often home-centered "sweat shop" system. Comprised of females and children working long hours under contract or subcontract, the production of saleable materials for large retail or wholesale outlets was extensive, occupying a range of living spaces from "the attic of a four-story building" to a "low, damp basement where artificial light had to be used during the entire day" (Government of Canada, 1882, p.4). Seven years later, a subsequent federal inquiry, the *Royal Commission on the Relations of Labor and Capital* provided additional evidence of the many young children "some not more than nine years old" working around dangerous machinery in cotton, glass, tobacco and cigar factories (Government of Canada, 1889, p.36). Documentation of the many children working from "six o'clock in the morning till six in the evening, with less than an hour for dinner" paled in comparison to testimonies of the routine beatings and imprisonment of children employed in many factories (Government of Canada, 1889, p.10, 36).

The widely unknown child labour trade underway across Canada between 1830 and 1940 further fueled the child labour force, with over 100,000 neglected and orphaned "waifs and straifs" (primarily from the United Kingdom and Ireland) shipped to Canada to be apprenticed as labourers and domestic servants (Kohli, 2003; Parker, 2008; Parr, 1980). Many of these child emigrant workers were also found to suffer sexual and physical assault (Parker, 2008). Taken together, it is no surprise that by the end of the 19th century, children were more likely than mothers to be the secondary wage workers after the adult husband in Canada. This labour served as the main source of additional support for urban families under economic stress (Haines, 1981).

By the early 20th century, attitudes had changed. Child labour was now seen as evil. Child labour committees proliferated feverishly across the United Sates working to position child labour "with all the institutions of evil memory – with bull baiting, witch-burning, and all other execrated customs of the past" (Markham in Zelizer, 1985, p. 62). Between 1880 and 1930, the gainful occupation rates of U.S. children fell dramatically from 32% to 6% for boys aged 10 to 15 and 12% to 2% for girls aged 10 to 15 (Carter & Sutch, 1996, p. 7).

Although such statistics are not available for the Canadian context, documentation suggests a similar process unfolded within Canada as evidenced by the federal *Report on Child Labour* (Ontario Committee on Child Labour, 1907). Despite labour commissions (Government of Canada, 1882, 1889) frowning upon the degrading treatment of child workers, it was not until the turn of the 20th century that labour inspectors began in force to halt child labour. More restrictive amendments were made to various provincial Factory Acts, improved enforcement and truancy regulations were noted, and additional labour inspectors were hired to afford inspectors the ability to conduct factory inspections "in a painstaking and conscientious manner" (Hurl, 1988, p. 98).

Research into the legislative processes behind the adoption of child labour laws across Canada reveals not only humanitarian concerns for protecting children in their tender years but also protecting adult working men's self-interests. As Hurl (1988) reveals, working class men facing hardships in the emerging industrial order were the first to formally organize an opposition to child labour. In an interesting parallel, Ursel (1992) reveals how women, who were also viewed as male competition in the early industrialization period, were similarly deemed to be at risk in the labour market. Alleged conclusive proof of irreparable damage to young women's health from sustained employment, premised on the ideals of the patriarchal family, served to officially promote a gendered division of labour in both the emerging industrial economy and labour organizations of the time (Ursel, 1992).

With traditional views of children's expulsion from the labour market focusing largely on key structural, often economic changes, Zelizer maintains that the "precise nature of the relationship between changes in the economic roles of women and children remains unclear and largely undocumented" (Zelizer, 1985, p. 9). For some theorists, children's expulsion was the consequence of industrial capitalism's success which required an increasingly skilled workforce, as well as rising real incomes which reduced the need for children's wages and increased the ability to send children to school full-time (Huber, 1976; Minge Kalman, 1978). For other theorists, it was simple land demography: declining land availability made the labour of children less important to family prosperity (Comacchio, 1999). For others still, children and women's labour market expulsion was a dual-purposed strategy reflecting a collaboration between capitalism and patriarchy. As Carl Degler (1980) reveals, "exalting the child went hand-in-hand with exalting the domestic role of women; each reinforced the other while together they raised domesticity within the family to a new and higher level of respectability" (p.72). The ensuing cult of domesticity[5] emerging from this dual exaltation purported to provide a "haven in a new heartless world" (Lasch, 1979, title). Not only did this reduce job competition for men but it also served to raise their wages with the ensuing implementation of the *family wage* – a wage sufficient for a male worker to maintain both himself and his dependent wife and children (Vosko, 2000). Rising to prominence

---

[5] The cult of domesticity or cult of true womanhood reveals the 19th century ideology identifying four characteristics supposedly central to women's identity: piety, purity, domesticity, and submissiveness, all of which served to isolate women in the home as guardians of their family, allegedly shielded from the degraded world of early industrialism. A true woman's role in life was to perform the domestic chores of the household all the while recognizing and respecting her inferiority and dependence on her husband (Welter, 1966).

in the post-Second World War era, the family wage served to further reinforce and sustain the ideology of domesticity and familialism by preserving women's so-called proper place in the domestic sphere.

Without agreeing on one key independent force behind the exodus of children from the labour market, Zelizer argues that all existing explanations fail to account for the *controversial* nature of the child labour movement. The "vehemence and urgency to remove all children from the labour market" resulted in a 50-year battle between the moral reformers of child labour and its defenders (Zelizer, 1985, p. 62). For Zelizer, this could only be explained by the new cultural equation introduced as follows: "If children were useful and produced money, they were not being properly loved" (Zelizer, 1985, p. 72). Coinciding with this revised social contract of children as extra-commercium (i.e., residing outside of the cold commercial world) was the codependent shift in what was deemed to be valid child labour. Children's removal from the labour market was substituted with their new place of employ within the *household.* Instead of earning money in the market, children were now paid an allowance for performing instructional (versus instrumental) tasks in the home that were meant to educate children instead of providing any real help to the mother and/or larger family unit. Tasks were to be limited and not unduly burdensome so as not to detract children from their social and educational development. By 1930, most children under the age of 14 were out of the labour market and in schools full-time (Zelizer, 1985). Child labour legislation continued to exempt certain types of work, mainly in newspaper distribution, motion pictures and theatres and agriculture, and only inasmuch as they were conducted *outside* of school hours.

One important area Zelizer herself acknowledges is the degree to which the lives of children continued to vary by social class and racialized ethnicity. Many working class and immigrant families were hit hard by children's removal from the labour market. Child labour legislation sparked quasi-riots among immigrant workers in the first few decades of the 20th century. In the United States, one New York canner, which attempted to exclude children under 10 from the sheds, found himself "besieged by angry Italian women, one of whom bit his finger 'right through'" (Yans-McLaughlin 1971, p.193). Other took to falsifying children's documentation[6] to circumvent U.S. anti-child labour laws. Loopholes in the law also permitted specific children to work during this budding period of anti-child labour "if their earnings were necessary for self-support or to assist their widowed mothers or disabled father" (Zelizer, 1985, p. 64).

In Canada, on-the-job report documentation from early labour inspectors reveals a similar awareness and sensitivity to family poverty. Many inspectors were noted to reluctantly, but frequently, turn a blind eye to the employment of children from poor families, particularly children of widows, whose welfare depended upon the earnings of their children (Hurl, 1988). Historical changes in ideologies of childhood thus had different consequences for different social and ethnic classes and at times, were circumvented according to economic considerations.

1.4 THE RISE OF YOUTH AND THE LENGTHENING OF CHILDHOOD

One byproduct of expelling all children from paid labour, incidentally, was the rise of new conceptions surrounding "youth" and the juvenile problem plaguing older, post-pubescent children in the early 20th century. The process of industrialization, and the ensuing shift from rural to urban city life, gave rise to a host of social problems, including sparse housing, overcrowding, health

---

[6] It has been noted that parents routinely sabotaged regulatory legislation by simply lying about their child's age, often aided and abetted by notary publics who produced false affidavits for a small illegal fee (Sands Johnson in Zelizer, 1985, p. 69).

problems, crime, dangerous labour practices, meager wages, and poor environmental conditions (Hartinger-Saunders, 2008). For the first time, cities had to contend with large numbers of homeless children, who unguided and often abandoned, formed juvenile street gangs that became a physical and verbally assaultive threat to the public (Regoli & Hewitt, 1997). Stealing and other forms of criminal behaviour became necessary survival mechanisms for a growing number of older children, often from urban slums located within large industrial cities (Agnew, 2001; Mays & Winfree, 2001). The mere presence of these unruly children became an issue for an increasingly nuisance and intimidated privileged class. It was not long before members of the upper and middle classes formed the child saving movement to simultaneously assist and control this subset of older children (Hartinger-Saunders, 2008).

It is in this landscape that the stage was set for G. Stanley Hall (1904) to coin the term "adolescence" to describe the so-called biological period of "storm and stress" brought about by changes beginning with puberty and ending with physiological and emotional maturity. For Hall, roughly beginning at age 14 and lasting up to as long as the age of 24, individuals would undergo changes that resulted in a so-called period of risky behaviour, mood swings and conflict with parents (1904). Around this same time, the juvenile problem became a key focus of the Chicago School of Sociology. The ethnographic research carried out by this group of Sociologists was an attempt to understand adolescent crime and deviance plaguing large U.S. industrial cities at the turn of the 20th century. Under the leadership of Robert E. Park, a variety of ethnographic accounts provided detailed descriptions of the budding youth problem, shedding light on key issues related to ghettos (Wirth, 1928), youth gangs (Thrasher, 1927; Whyte, 1943) and urban youth nightlife (Cressey, 1932) in early industrial metropolises. These studies linked the explosive growth of big cities (and the shift from rural to urban community living) to the emerging host of social problems among this urban youth population. Importantly, the oft-noted juvenile problem was mediated by social class and ethnicity, with a dominant focus on economically and ethnically marginalized youth. In what is considered one of earliest and most influential study on gangs: *The Gang: A Study of 1,313 Gangs in Chicago* (1927), Frederick Milton Thrasher contends that urban youth gangs were localized to neighborhoods in flux, mainly those comprised of ethnically and economically impoverished immigrants. Illustrating this general theme of the poor, immigrant youth problem, Thrasher draws on the practically “gangless” nature of “purely residential and well-organized suburbs” comprised of predominantly middle to upper class families to illustrate his thesis (Thrasher, 1927, p. 20).

It is only over these first few decades of the 20th century, therefore, that we see the development of “youth” as a separate, and similarly socially constructed concept to represent an intermediary phase between childhood and adulthood (Furlong, 2013). The concept of “teen-age” would next emerge, first documented in a 1926 edition of the Boy Scouts of America Handbook before gaining wider momentum in the 1940s (Dalzell, 2012). By 1942, Talcott Parsons would coin the term “youth culture” to signify the set of patterns and behaviour phenomena that link up to the breaking away from a relationship of dependency with the childhood family and the move to marriage, parenthood and career (Parsons, 1942, p. 606). It is in this landscape that the Centre of Contemporary Cultural Studies (CCCS), founded in 1964 at Birmingham University, would focus its efforts on adolescence as a form of collective subcultural rebellion (Hodkinson & Deicke, 2007). Spearheaded by researchers such as Phil Cohen, Gary Clark, and Dick Hebdige, the CCCS would connect a host of emerging youth problems to new social and economic realities of the post-World War II era. Employing a Marxist approach, CCCS theorists explained the rise of deviant youth subcultures across the United Kingdom as a response to the status frustration experienced by youth in modern capitalist society. In effect, youth's behaviour was viewed as a problem-solving device of the blocked futures they experienced under modern capitalism (Cohen, 1955; Murdock in Brake, 1980).

Similar to childhood, youth and adolescence became concepts wrought with ambiguity. There were no clearly defined chronological markers for these emerging concepts. Instead, the period of semi-dependence between the full dependence characterizing childhood and the full independence of adulthood, varied by time and location and was "impossible to define clearly except in terms of the legal definitions of the maturity age" (Heinz, 2009, p.4). What this new category of "youth" reveals, more generally, is the lengthening of the broader childhood umbrella to account for increasingly stalled pathways to adulthood and full dependence. New demographic, labour and social practices and policies triggered by the shift to an industrial order served to lengthen the period of semi-independence ahead of full independence for a growing portion of teenage youth who, a century prior, would have already transitioned into full adulthood (Heinz, 2008). The resulting differentiation of this largely older, post-pubescent group of children thus parallels the earlier invention of "childhood", both reflecting changes connected with the industrial revolution and modern capitalism.

1.5 CONCLUSION: CHILDHOOD FROM THE POSTWAR TO THE PRESENT

When analyzing the ideology of the sacred child, historians note its precariousness moving into the 20th and 21st centuries. In *The Sociological Imagination* (1959), C. Wright Mills forewarned that the modern age was being succeeded by what he called a "postmodern" period marked by the rise of multinational corporations, a decline in social welfare systems, and a restriction of individual freedom and choice. Emerging societies would require conceptual transformations in the expectations, images and standard categories of thought and of feeling. Subsequently, he wondered what type of man, woman, and child would appear in this new fourth epoch of human history. Although different scholars put forward different rationales for the changing conceptions of childhood beyond the 21st century, they all agreed that change would come.

For Neil Postman (1982), the modern ideology of childhood is quickly disappearing due to the age of electronic media and the serious challenges posed to both the authority of adulthood and the curiosity of children. By eliminating the exclusivity of knowledge that defines adults as a group, Postman argues that television, which became firmly rooted in American life by 1950, led to a homogenization of mentalities that gave rise to the “adultified child” and the “childified adult” – byproducts of a communication medium that made distinctions among age groups appear invidious (Postman, 1982, p. 88, 124). Evidence of the changing cultural conceptions around youth and adulthood include the form and content of media that promotes the unseating of childhood, the merging of tastes and styles of adults and children, the changing treatment of children by various institutions (e.g., the courts which increasingly treat children as adults) and the ‘hard facts’ surrounding youth’s lifestyle –criminality, alcohol and drug use, increased sexuality and teenage pregnancy. With these changes, Postman contends that the dividing line between childhood and adulthood is fast vanishing and that we are currently faced with the possibility that modern notions of childhood are “a transitory aberration in cultural history, like the horse-drawn carriage or black scribbles on white paper” (Postman, 1982, p.144).

Stearns (2010) contends that modern industrial society has led to an increasing ambivalence and even hostility to childhood. The sheer decline in the numbers of children becomes inexorably linked with newer economic calculations about children’s usefulness relative to their costs. A glaring juxtaposition can be made with the “wished child” (or Wunschkind in German) in agricultural society and the identification of a phenomenon Germans coined “Kinderfeindlichkeit” in the 1970s (defined as a hostility towards children) manifested particularly by couples avowing parenting altogether (Stearns, 2010, p. 131).

Like Postman, Zelizer also foreshadows the demise of the sacred child when she warns the readers that “in the 1980s, the sacred, economically useless child may have become a luxury or indulgence that the contemporary family no longer values, nor in fact, can afford” (Zelizer, 1985, p. 208). Zelizer wonders if new family structures and ideologies of domestic democracy arising out of women’s increased employment would give rise to a part-time househusband and housechild. Would the sentimental value of children, who previously served as a “bulwark” against the market, crumble under the pressure of advanced global capitalism and more recent socio-cultural changes? (Zelizer 1985, p. 211). Or, would children’s emotional sacred value remain intact as their instrumental worth shifted?

In order to situate children and youth’s caregiving within the context of advanced industrialism, we must now turn to the economic and noneconomic shifts occurring across Canada since the publication of Zelizer’s research three decades ago. Only then can we get a better sense of just how increases in the numbers of youth caregivers is triggered by structures borne out of more advanced global capitalism.

CHAPTER TWO

Globalization, the New Economy and the Changing Childhood Contract in Canada.

As childhood scholars have taught us, historical analyses of childhood cannot be understood without mapping the changing roles of children onto a macrostructural analysis of society (Qvortrup, 1999). Connecting changing conceptions surrounding childhood to evolving economic, political, demographic and socio-cultural transformations, triggered by advanced global capitalism, allows us to understand why many families are seeking a revised childhood contract. This chapter will provide supporting evidence for how recent economic and noneconomic changes have forced a re-evaluation of what is increasingly considered acceptable and necessary child labour in the West, more broadly, and in Canada more specifically.

2.1 ECONOMIC

When Zelizer pondered whether new family structures and ideologies of domestic democracy would arise out of women's increased employment in the 20th century, the effects of global capitalism and the shift to the New Economy (NE) had yet to fully unfold. Shifting landscapes within the global economy over the past forty years have not only pulled additional numbers of women into the labour market but have also kept them and their working spouses out of the household for longer periods of time, impacting their need to rely on their children's labour.

The NE represents a social, political and economic transition from a manufacturing-based economy to a service-based economy. NE entered the labour lexicon in the 1990s to reflect the effects of advancements in information and communication technologies (ICTs) and the massive global economic integration flowing from these innovations. ICTs, including the PC, cell-phone and mobile internet, rapidly changed the collection, transmission and storage of information and eroded the constraints of time and space that had previously prevented a wider global integration of markets. In order to understand how the NE creates tensions for the provision of reproductive labour, we must take a closer look at its three defining features: (1) a globalized economy; (2) a form of politics that includes the demise of the welfare state based on Keynesian economics and the rise of the neoliberal state and (3) restructured forms of service work tied to the mass mobilization of women in the labour force (Broad & Hunter, 2010).

2.1.1. The Globalized Economy

A number of processes converged to provoke and facilitate the global integration of markets. First, and not long after World War II, the development of containerisation[7] enabled parts to be made in Mexico (or anywhere in the world where labour and raw materials were cheap) to be brought back to the United States or Canada for final assembly and sale. Second, the period of economic downturn commencing in the 1970s, prompted by the 'Volcker shock' in the United States that radically drove up world interest rates in 1981-1982, provided the key trigger for the West to seek out cheaper global markets with which to produce goods. It also spurred on the "employers' offensive" that was launched to break workers' wage expectations and power (Albo, 2008, p. 5). Third, the introduction and development of ICTs provided the final and primary vehicle with which capital has been able to restructure labour forms now available in post-industrial capitalism. With the combination of three forces – digitization (information technology), telecommunications (communications technology) and the creation of financial inventions such as

---

[7] Containerisation is a system of freight transport based on a range of steel intermodal containers built to standardised dimensions, which are then loaded, stacked, and transported efficiently over long distances, and transferred from one mode of transport to another (via ships, rail and semi-trailer trucks). The system, developed after World War II, led to greatly reduced transport costs, and supported a vast increase in international trade (Cudahy, 2006)

securization (which liquefied hitherto unliquid capital, allowing it to circulate faster) – work was now able to be relocated to any locale where there was a ready supply of workers and a suitable infrastructure (Huws & Dahlmann, 2011; Sassen, 1998).

The resulting "new international division of labour" (NIDL), a term used to describe the increasing numbers of jobs relocated to less developed countries in the Global South, revolutionized business practices by breaking up the labour process into separate components, which are then outsourced and relocated (Mies, 1986). The ensuing creation of highly elaborate *global value chains*, defined as the sum total of the processes that go into producing a final product or service (Gereffi et al., 2005; Huws & Dahlmann, 2011), accelerated at a dizzying rate. A "dominance effect" would soon unfold with companies eager to emulate what was being done by other industry leaders via large-scale offshore outsourcing of standardized internal functions (Standing 2011, p. 33).

In the West, this resulted in the elimination of the once-central economies of scale form of production and its replacement with a system based on economies of scope, with "just-in-time" production replacing the buffer stocks and inventories of the past. This form of production came to represent the burgeoning knowledge-intensive service sector in the West, which was allegedly based on intelligent cooperation, multi-skilling, a flattened management system and quality control (Armstrong & Armstrong, 2010, p. 21). Offshoring the industrialized manufacturing sector allowed capital to instantly eliminate a host of well-paying, unionized jobs, to be replaced with an expanding glut of precarious service-sector jobs carrying multiple forms of labour-related insecurity. Additionally, outsourcing to less regulated, poorly paid countries of the global south allowed capital to circumvent established labour laws and regulations secured by industrialized workers in the north.

The ensuing structural shift towards "flexible production"[8] (via outsourcing, temporary work and independent subcontracting through self-employers) and internal flexibility through the expansion of part-time, casual and contract work contributed to the progressive dismantling of the standard employment relationship (SER). The existing SER, which saw a worker (often a male) work full-time, year-round and indefinitely for one employer and normally on that employer's premises while enjoying extensive statutory benefits and entitlements (Cranford, Vosko & Zukewich, 2003; Vosko, 2006) would begin to vanish under globalization. Moreover, the changing SER and re-orienting of workplaces not only contributed to de-unionization and prevented re-unionization, but also promoted additional declines. Global value chains removed groups of workers from close proximity to one another, thus reducing opportunities for mobilization. Domestic layoffs of full-time, union jobs and their replacement with part-time, temporary and casual jobs added to the unwillingness of domestic labour to mobilize. In Canada alone, the overall unionization rate fell in Canada from 38% to 30% from 1981 to 2012, a decline of 8 percentage points (Galarneau & Sohn, 2013).

Under globalization, immensely powerful transnational corporations (TNCs), the likes of which were unimaginable half a century ago, achieved considerable economies of scale and amassed enormous profits. In 2001, the top 1000 TNCs owned assets of $41 trillion, or "over 80% of the world's developed resources, production equipment, and debts" (Gelinas, 2003, p.58). By working in conjunction with international financial institutions, and through associations (the Trilateral Commission) and forums (Davos), these corporate powerhouses displayed "a

---

[8] This is not to be confused with *employee-driven* flexibility which involves in-house strategies such as: compressed workweeks (working extra time each day to reduce the number of days in the workweek), flextime (the ability to determine when you begin and end your work day), telecommuting (working some hours from home) and job sharing (where two people are retained on a reduced-time basis to perform a job normally fulfilled by one person working full-time) (Van Eyck, 2003).

convergence of shared interests" in the pursuit of profit, power, and control in the global economy (Gelinas, 2003, p.63). This heightened power provided greater ease with which to influence change at the state level, evidenced by the co-occurring rise of the neoliberal state apparatus in the West.

2.1.2 The rise of the neoliberal state

Labour changes in the West were ideologically propelled by neoliberalism. The central idea of neoliberalism remains that economic development and growth depends on market competitiveness. Along these lines, if Western industrialized countries did not roll back social security benefits and tame unions, de-industrialization would accelerate, unemployment would rise, economic growth would slow, and poverty would escalate (Standing, 2011). Initially advanced most forcefully by the Thatcher and Reagan conservative regimes of the 1980s, neoliberalism's withdrawal from state roles and responsibilities involved a re-orientation of fiscal and monetary policies to intensify labour discipline while shifting tax burdens away from the wealthiest factions of society to the middle and working classes. Tariffs against imported goods soon vanished. Free trade policies were forged by nation states to reinforce capital internationalization. Relentless employer-driven attacks on domestic labour were backed by government policies. In Canada, increases to essential workforce (or back-to-work) designations for public sector employees occurred and prominent union leaders were jailed for defying such legislation. In the end, workers' collective rights and power were weakened (Clawson, 2003; Panitch & Swartz, 2008).

Massive increases in immigration maximized profit through what Karl Marx called "industrial reserve armies" comprised of the most disadvantaged members of society who are "flexible, docile, manipulable and skilled labourers when necessary" (Harvey, 2008, p. 58). The use of migrant and temporary workforces reached unprecedented levels in the NE, secured through migrant labour programs and temporary staffing agencies advocated by state and business interests. While states cite an alleged fiscal responsibility to reduce deficits, businesses seek legislative changes in order to increase profit. The cost advantages are clear: wages are lowered, experience-rated pay is avoided, entitlements to enterprise benefits are absent, and workers are more easily induced to work harder for fear of being sent home (Standing, 2011). In Canada, this strategy was kicked into gear with the 1973 Non-Immigrant Employment Authorization Program (NIEAP) that set into motion a clear shift in immigration policy away from permanent immigrant settlement towards an increasing reliance on temporary migrant workforces designed around short-term, low skill work in various agricultural, social service and care industries (Sharma, 2006).

2.1.3. The rise of the service industry and the mass mobilization of women into the NE

The NE cannot be discussed without highlighting the unprecedented mobilization of women, who now provide the backbone of the global workforce (Acker, 2004; Harvey, 2010; Pupo & Thomas, 2011; Sassen, 1998; Shalla, 2010; Sharma, 2006; Standing, 1999, 2011). It is no secret that globalization's transfer of production from the West to developing countries was based "quite shamelessly on the organization of young women as a precariat, mobilized to labour for a pittance and not expected to stay in jobs for long" (Standing, 2011, p.60). Chosen for their historical definition as housewives which rendered a cheaper buying price for their labour (Mies, 1986), women comprise upwards of 70% of the mainly American, German and Japanese-owned factories that have relocated to the Philippines, Malaysia, South Korea, Singapore, Mexico, Sri Lanka and Thailand (Standing, 2011). The result of this has been a twofold global feminization of labour, including both a rise in the total female labour force participation and the erosion of many full-time, permanent jobs traditionally held by men (Armstrong, 1989; Standing, 1999). The resulting elimination of the previous male-dominated SER and its replacement with a female-dominated non-standard, precarious alternative, comprised of temporary, seasonal, casual or contract work in addition to 'own-account' self-employment and multiple job holding (Cranford, Vosko & Zukewich, 2003; Vosko, 2006) has consequences for workers. Employees are increasingly faced with variable work schedules, reduced job security, lower wages, hazards at the workplace and stressful psychosocial working conditions (Benach & Muntaner, 2007; Van Eyck, 2003).

Feminist political economists have argued that economic restructuring is *a women's issue*: neoliberal policies and economic retrenchment have affected women the hardest by reducing the number and range of good jobs within public services in traditional areas of female employment (health, social services, education) (Stinson, 2004). With clawbacks in the public sector, the majority of women turn to more precarious sales and service occupations, a hallmark of the NE, for employment opportunities.

Precariousness is shaped not only by gender but also by race and immigrant status (Cranford, Vosko & Zukewich, 2003; Vosko, 2006). To illustrate, a recent analysis of precarious jobs by industry and occupation reveals that employment in *Accommodation and Food Services* industries is the most likely to be precarious, with the typical worker being a woman and a woman who has schooling amounting to a high-school diploma or less (Noack & Vosko, 2011). Racialized women, and workers from South Asian and Filipino backgrounds are overrepresented in this industry as are women who have immigrated to Canada in the past 10 years (Noack & Vosko, 2011). Income data allows us to appreciate how these changes have disproportionately affected women. In Ontario for example, women in sales and service occupations earn an average of $17,400 less than their male counterparts, comprising a gender pay gap of 48% (Cornish, 2016).

2.1.4 The decade of change

The shift to the NE culminated in a "decade of change" in the 1990s in which a greater proportion of workers, especially women, experienced challenges balancing paid and unpaid work obligations, increased stress, decreased satisfaction with work, and declining physical and mental health (Barling, Kelloway & Frone, 2005; Canadian Index of Wellbeing, 2010; Duxbury & Higgins, 2008; 2012b; Green, 2006; Lowe, 2008; Vanier Institute, 2010). Indeed, the popularity of discourses surrounding questions of work-life balance is testament to the growing challenges Canadians face in managing their various roles (e.g., employee, parent, caregiver). A 2012 survey of 25,000 Canadians employed full time for 71 public, private and not-for-profit organizations reveals that in spite of work demands and hours worked per week rising, flexible work arrangements (e.g., compressed work weeks, tele-commuting, flexi-time schemes) remain rare (Duxbury & Higgins 2001;2012b). Such results tend to apply to those workers who have been able to retain or acquire the remaining "good jobs" [9] and reflect one half of an increasingly polarized workforce. Pursuant to this, there are managers and professionals who experience increased work hours juxtaposed with those less-skilled, precariously employed workers who experienced decreasing work hours (Green & Sand 2015; Kuhn, 1996; Lowe, 2008; Walks, 2013). Even for full-time employees whose work hours have not necessarily risen, the intensification of work linked to rising performance expectations and workloads has placed different pressures on the typical 37.5-hour week today compared to 10 or 15 years ago (Burchell, Ladipo & Wilkinson, 2002; Lowe, 2008).

---

[9] According to the Economic Council of Canada in the Good Jobs, Bad Jobs report published in 1990, "Good Jobs" refer to those associated with full-time, permanent position, with good pay and benefits (Maxwell in Lowe & Schellenberg, 2005, p. ix)

Sharp increases in the price of basic necessities of life have also made it harder for working adults to support their families. A recent report by the Canadian Centre for Policy Alternatives reveals that a family of four in Toronto needs an annual combined employment income of around $72,000 to afford the basics, such as rent, transportation, child care, food and clothing (Tiessen, 2015). The median after-tax income of Canadian economic families in 2013 was $53,500 (Statistics Canada, 2015a). This helps to explain why Canadians are also lengthening their career trajectories and delaying retirement. The previous trend of early retirement in the 1980s and early 1990s has reversed in recent decades. From 1997 to 2010, post-retirement employment rose from 30.5% to 39.4% for men and from 15.8% to 28.6% for women (Carriere & Galarneau, 2011). Financial pressures (38%) are cited as the main reason for post-retirement employment among Canadians (Schellenberg, Turcotte & Ram, 2005). This pattern contributes to a reduction in the availability of healthy older Canadians to provide caregiving or childcare for their spouses and/or grandchildren. Shedding light on the changing lives of parents consequently reveals a great deal about the changing lives of children.

At the same time that economic restructuring keeps adults employed outside of the household for longer periods, the opposite trend has occurred for youth under the age of 25 years. Youth unemployment and underemployment represent two of the most troubling and persistent issues cited with the NE. On a global scale, the International Labour Organization (ILO) reports that 73.4 million young people were unemployed worldwide between 2008 and 2012, reflecting a 25% increase within advanced economies (ILO, 2013, p.3). Canadian research corroborates these findings. Labour Force Survey data show that the rate of temporary, contract and term employment has increased at a faster pace among younger workers than older workers. The proportion of employees under the age of 30 working in non-permanent jobs nearly doubled from 6.9% in 1997 to 11.6% in 2011 compared to a much smaller 4.0% to 5.7% growth for those aged 30 and older (Foster, 2012, p.3). The rise of discouraged youth, those who are not in employment, training or education, has become a crisis. There is no shortage of news stories revealing how crippling debt attained through prolonged education, the rise of low-paying, short-term and insecure work, and the cost of food, tuition and housing have led Canada's youth to lose hope for the future (Grant & McFarland, 2012). The reality of youth under– and unemployed is such an emotionally charged and pressing problem that Bank of Canada Governor Stephen Poloz sparked a firestorm of criticism when he suggested that young people work for free as a way to avoid the scarring effect of prolonged unemployment (Grant, 2014).

2.2 NON-ECONOMIC CHANGE

As useful as it is to collapse categories for purposes of discussion, there is an inevitable and sometimes deliberate interpenetration of the social, political and economic realms. Global capitalist economic restructuring has not been alleviated by implementing social policies. As Broad and Hunter (2010) reveal, fully comprehending the effects of the NE involve an understanding of the relationship among governments, welfare states, and businesses and the corresponding socio-cultural change resulting from these.

2.2.1 Political

Public welfare policy has been re-designed in accordance with employers' needs for flexibility and free trade of goods and services. The modern Canadian welfare state (i.e., the legislatively sanctioned and publicly or quasi-publicly administered spending on welfare benefits in the areas of health, education, social assistance, unemployment, pensions etc.) has seen its funding structures and program delivery re-fashioned. What was once a "needs-based" system grounded in social entitlement and labour-market exclusion programs has shifted towards models emphasizing selective entitlements, active programming, and maximum participation in wage labour (Broad & Hunter, 2010, p. 29).

After the Second World War, social assistance or welfare was deemed a necessary component of the 'class compromise' made between capital and labour to "assert the primacy of government in the field of social welfare" (Katz in Broad & Hunter, 2011, p. 26). Today, social welfare is criticized as a system promoting dependency. A new language of social inclusion has been adopted to justify the removal of no strings attached welfare. The implementation of *workfare* now forces social assistance recipient's work in order to receive benefits as a so-called way to draw people into the larger community. Despite the overwhelming body of literature demonstrating the ineffectiveness of workfare programs (National Union Research, 2000), most Canadian jurisdictions employ them. Workfare thus becomes part of a broader low-wage strategy of the political right to assist labour in driving down wages and providing a pool of cheap labour through the denial of collective social rights (Dunlop, 2006; Esping-Anderson, 1990; Klein & Montgomerey, 2001, p. 5).

In this landscape, economic restructuring accelerates the dismantling of the welfare state under neoliberalism and widens the gap between affluent and impoverished childhoods (Thorne, 2012. Canadian evidence supports the increasing need and desire to reformulate children's usefulness, with four key areas chosen for discussion: (1) the lack of policies aimed at addressing women's *en masse* transition to the paid labour market; (2) recent healthcare and social service cuts; (3) the increased institutionalization of unpaid work, and (4) the loosening of provincial child labour laws.

2.2.1.1 Policies supporting women's foray into paid labour

The first, and arguably strongest, predictor of an increased reliance on children's usefulness involves the movement of their mothers out of the household and into the labour market. During the Second World War, women moved into well-paying jobs to fill the gaps left by their husbands fighting on the front lines. The collective exposure to men's high wages and the socializing aspects of their work outside the home heightened married women's expectations for their daughters to pursue higher education and to have careers (Armstrong & Armstrong, 2010; Gluck, 1987). This experience, combined with the subsequent gains made by the second wave of the women's movement in the 1960s and the shift in employment from a goods-producing to a services-producing sector, meant that women were willing to enter many of the 3.2 million new jobs created between 1946 and 1960 (Statistics Canada, 2000). Even though single women participated in the labour force to a considerable degree during the 1940s, fewer than 4% of married women were in the labour force in 1941 (Morissette & Galarneau, 2016). By 1980, that proportion had jumped to over half of all married women and continued to rise to over 88% of Canadian-born married women and 76% of foreign-born wives by 2014 (Morissette & Galarneau, 2016).

What did not follow this massive structural shift, however, were state-based supports to help mitigate some of the reproductive labour lost in the process. The state was thus complicit in supporting a double burden which effectively stalled the revolution in the advancement of equality between the sexes (Hochschild & Machung, 1989). When Hochschild and Machung (1989) first discussed the issue 28 years ago, they were referring to the fact that even though women were moving into full-time, often male-dominated occupations, men had yet to shift into female-dominated ones nor had they modified their housework or childcare contributions. Out of this landscape of fast-changing women amidst slow-changing men came the discovery of women's "second shift"[10]. Women would work a full day at their paid jobs only to come home and work another unpaid domestic shift in the household, amounting to the equivalent of an extra month of 24-hour days more per year compared to their spouses (Hochschild & Machung, 1989).

The lack of progress and support in the area of childcare, in addition to reasonably priced housing closer to places of work, community-based meal and laundry services, transportation assistance for seniors' medical needs, and translation services for the increasing numbers of new immigrants to Canada all contribute to women's persistent double burden.

2.2.1.2 Cutbacks to healthcare and social services

Central to neoliberalism is a re-conceptualization of health and social care from being a public right to a private responsibility. Recent neoliberal-inspired health and social care restructuring in Canada, particularly the transition from institutional to home-care and the ever-growing privatization of services, returns the responsibility for caring to families and communities. Increasing state demands for the uptake of de-listed services places stress on the non-profit and voluntary sector. To be discussed in greater depth in Chapter Six, this movement is problematic given the non-commensurate increases to community funding and agency resources (Scott, 2003).

Privatization of health and social care sees the application of a business model, evidenced by the increasing use of "business plans," "business strategies," "product lines" and "outcomes" justified along the lines of creating more efficient and effective health and social care workplaces (Armstrong in Ginden et al., 2005; Gibson, O'Donnell & Rideout, 2007). These changes occur in an increasingly private and non-patient-centred manner. The privatization of decision-making at the state and business level means that fewer decisions are open to public scrutiny, which tends to

---

[10] Incidentally the title of Hochschild and Machung's much celebrated 1989 book.

allow those persons with the most resources to seek fiscal cost-saving goals that are often antithetical to the needs of patients and people providing care (Armstrong in Ginden et al., 2005). The "leaner and meaner" workplaces (Pupo & Thomas, 2010, p. xiv) that result from such restructuring focus on achieving market-based efficiencies at a cost to patient outcomes. For the majority of female staff in health, education and social welfare professions, time-motion studies[11] aimed at reorganizing, controlling and speeding up healthcare work result in care providers "with no time to care" and "not enough hands" (Armstrong in Ginden et al., 2005, p. 15). Healthcare providers feel guilt due to the degraded quality of care they must provide and patients receive a poorer quality of care in return. The documented effects to the quality of care Canadians receive as a result of such cutbacks include: poorer patient quality, increased patient suffering, dissatisfaction and inconvenience, increased morbidity and mortality, contribution to infectious disease outbreaks in hospitals, violence aimed at hospital staff and physicians, decreased physician and nursing productivity, and increased risk of medical error (Ontario Health Coalition, 2016).

Focusing on health and social care delivery, the ideology and practice of neoliberalism exacerbates youth-based caregiving in three separate but related areas: the privatization of costs, the privatization of service delivery and the re-privatization of care work (Armstrong in Gindin et al., 2005, p. 12). First, the progressive de-listing of certain "medically necessary" hospital and physician services from the Canada Health Act has led to the charging of added fees and sometimes even the entire cost of services and tests that once were covered free of charge. People must either rely on their insurance companies to cover extra costs and/or go without care altogether (Gindin et al., 2005). Pushing people out of hospitals sooner and into home-based models of health and

---

[11] Time motion studies were first described in the early 20th century under the emerging "scientific management" field. Here, quantitative data collection methods are used by an external observer to capture detailed data on the duration and movements required to accomplish a specific task, with the goal of reduce processes' times and improving so-called efficiency (Lopetegui, Yen, Lai, Jeffries, Embi & Payne, 2014).

social care delivery increases individual costs since medicines and other related health aids are no longer covered. In the absence of resources to pay for medicines and assistive aids, chronically ill persons require longer periods of recovery time and more unpaid caregiving in order to heal. Given that women tend to have fewer economic resources than men and are less likely to have private insurance plans to cover these extra costs (tied to their predominant responsibility for reproductive labour that keeps them out of the paid labour market for long periods of time), they suffer the most from this form of privatization (Gindin et al., 2005).

The second area of privatization is captured by the shift from not-for-profit to for-profit health and social service delivery. The contracting out of healthcare services via public-private partnerships results in costlier yet poorer quality of care provided by a mainly female labour force who are paid significantly less than women employed in the public, not-for-profit sector (Auerbach, 2002; CUPE, 2011; Gindin et al., 2005). Healthcare services deemed "ancillary"[12] and subsequently the first to be outsourced are those characteristically defined as "women's work", followed next by those deemed low or unskilled, both of which result in the loss of tens of thousands of stable, well-paid union jobs held mostly by women (Armstrong in Gindin, 2005). A feminist political economy lens is crucial in highlighting how these processes not only impact the quality of care and unmet care needs of all Canadians but how women have faced a double disadvantage in this process. It is predominantly women's jobs that have been outsourced, which has led to a decrease in women's wages, the elimination of benefits, and a decrease in job security (Armstrong in Ginden et al., 2005).

Finally, the re-privatization of care work from institutional settings back into the household and/or community is deemed a necessary and preferred state cost-cutting measure. This shift is

---

[12] Most frequently to be contracted out are those cooking, cleaning and laundry jobs (Armstrong in Gindin, 2005).

bolstered by an ideology that says institutional care is of poorer quality while care in the community or at home is of a higher quality. The ethic of individualism underlying neoliberalism reinforces re-privatization by expanding media and state-based calls for individuals to assume a greater responsibility for their own health. A book published by the Fraser Institute and written by former Ontario premier Mike Harris and former conservative MP Preston Manning typifies this standpoint: "We Canadians should assume greater personal responsibility for our own health and that of our families. But to do so, we must also have greater freedom to choose the health-care services we desire. Federal fiat should not limit our choice to a government monopoly" (Harris & Manning, 2007, p. 76). Satisfying the added individual responsibility for one's health via the return of care back into the household amounts to the conscription of women back into unpaid care work. It also, moreover, disregards the difficulty and skill required of homecare and the injustice of placing the onus for its completion on women as something they are *hard-wired* to do:

> …and there is nothing natural, traditional or unskilled about cleaning catheters, applying oxygen masks and dressing wounds. In spite of talk about returning care to the home, most of this new care work was never done there and there is no evidence that the care provided in the past was all good care. But this does not prevent women being blamed for not providing care nor does it prevent them from feeling guilty (Armstrong in Ginden et al., 2005, p. 16).

Not only has re-privatization eroded good jobs for women in the public sector, as well as decreased the range of public services designed to support their participation in the labour market, but it has led to more people being sent home from health care facilities "quicker and sicker" (Armstrong in Silversides 2000, p. 40). This neoliberalization of healthcare and social service delivery across Canada disproportionately impacts women. Destabilizing good paid employment options for women and intensifying women's care and support duties at home increases and intensifies the amount of reproductive labour they already provide. It is unsurprising, therefore, to learn that recent research reveals it is Canadian women who experience the greatest time crunch alongside significant drops in their leisure time (Canadian Index of Wellbeing Network, 2010).

Taken together, it is understandable why Canadian families are increasingly forced to rely on either the unpaid care of relatives and friends, mostly women, or on paid care provided by the for-profit sector. Those families where one or more members suffer from a chronic illness, disability, mental health issue or problem with alcohol and/or other drugs suffer the hardest from such cutbacks. If we factor in the growing contingent of seniors and the corresponding lack of affordable, accessible and safe long-term care, it becomes clear how the reliance on young people has become an increasingly viable and necessary alternative for the growing healthcare needs of Canadians.

2.2.1.3 The institutionalization of unpaid work

A system of state-coordinated workfare targeting youth has extended the range of work deemed acceptable for Canadian children. As Pupo and Duffy (2012) reveal, outside of total institutions, such as prisons and youth homes, which have traditionally mandated unpaid work, unpaid work is increasingly justified by new discourses surrounding citizenship, maturity, and education. The most glaring example of this is the relatively new requirement of community service among high school youth in order to graduate. The mandating of voluntary community work among high school youth across Canada is seen as a dual-purposed strategy that not only benefits youth but also the larger community. As noted by Volunteer Canada:

> If we engage youth effectively, we can keep Canada’s voluntary sector strong. As many of Canada’s seniors retire from their volunteer careers, youth will have a vital role to play in building healthy and resilient communities. (Volunteer Canada, n.d.)

The requirement of community service varies provincially and ranges from 40 hours of volunteer community service in Ontario to 30 hours in B.C and Newfoundland and Labrador (though B.C counts paid work as well) and 25 hours in the Northwest Territories (Sagan, 2015). If volunteer community work was proven to improve future civic attitudes and voluntarism, then there may be justification for its maturational value. Instead, recent research using a quasi-experimental design of two cohorts of Ontarian graduating youth – one compelled to complete the mandated community service requirement and the other not compelled – discovered no differences in current attitudes and civic engagement that might plausibly be attributed to participation in the program (Henderson, Brown, Pancer & Ellis-Hale, 2007). The only conditional impact observed between volunteer work and subsequent civic engagement was found for those youth who considered the experience to be positive and had a sustained commitment to one organization (Henderson, Brown, Pancer & Ellis-Hale, 2007, p.25). Arguably, this latter group of youth represents a qualitatively different cohort of volunteers who likely would be involved in the community without having to be mandated to do so. For the remaining majority, it is likely they share the experiences of the many who struggle to complete their mandated hours at the last minute, with provinces having to take steps to help students complete their hours. As the Toronto District School Board's program coordinator of Guidance, Career and Adolescent Development admitted,

> Some don't know what to do, and scramble over the summer to get their hours by Aug. 31 so they can graduate. It works out to just 10 hours a year — an hour a month during the school year – but some families may not be as rich in the ways they can access these sorts of opportunities (Cited in Brown, 2013).

A more plausible rationale for mandating volunteer work in areas of community or "civic engagement" for high school students, involves the guaranteed steady stream of unpaid workers it provides for the non-profit and voluntary sector which is chronically under-resourced. Voluntary work is positioned as a valuable learning tool for students who are viewed as having a safe environment outside the home to gain prospective "hands-on" work experience. In addition, it satisfies the growing moral debate, often couched in contemporary educational discourses, which cites a so-called crisis in citizenship among allegedly ignorant, indifferent, or apolitical youth whose lack of basic civic knowledge must be obtained by mandatory civic engagement as a marker of maturity (Condor, Gibson, O'Donnell & Rideout, 2007).

2.2.1.4 The loosening of provincial child labour laws

Changes in child labour legislation reveal a shrinking of the state's role in overseeing the labour of children. Since the early 1900s, Canadian legislation has regulated children's labour through an amalgam of labour standards, school attendance requirements, child welfare, and occupational health and safety legislation, which varies provincially and contains exceptions (Barnetson, 2010). Compared to a time when parents were vilified and sanctioned by the state for employing their children, legislation today has become so patchwork and conditional that most children can be employed with merely the consent of a parent or guardian and/or a permit from the province in question.

In 2004, British Columbia gained attention with its introduction of Bill 37, which granted children as young as 12 years of age allowance to work as many hours as adults in a full-time job. Previously, children aged 12 to 14 years required a permit from the Ministry of Skills Development and Labour, in addition to permission from both parents and school authorities in order to work. The Director of Employment Standards could additionally impose conditions related to appropriate tasks, hours of work, and even transportation to and from the work site (Luke & Moore, 2004). Under Bill 37, however, children under the age of 15 today may work with only the consent of one parent or guardian and are additionally unbound by previously prohibited occupations or activities (e.g. using power tools or selling door-to-door). Children can be also employed for longer periods of time in a given week: up to four hours on a school day; up to 20 hours a week when school is in session; up to seven hours on a non-school day; or up to 35 hours a week when school is not in session (Luke & Moore, 2004). This legislation positions British Columbia to have the lowest child labour standards in all of North America.

In a policy brief commissioned by the Canadian Centre for Policy Alternatives on Bill 37, Luke & Moore (2004) highlight how Bill 37 transformed the significance of child employment in the economy. First, it shifted child employment from an opportunity to learn or earn spending money, to a source of cheap labour for low-skilled employment. Second, it set the stage for the "many low-income families in BC" to supplement their incomes with that of their children's:

> Twelve-year-olds paid the First Job/Work Entry minimum wage of $6 an hour can earn, even with limits of 20 hours a week, about $480 a month during the school year. During their summer vacation, they could gross about $900 a month. A child's income could considerably boost the overall earnings of low-income families. The temptation for children to work at a younger age, for longer hours, at low-skilled jobs may prove too much for many low-income families who are struggling in BC. (Luke & Moore, 2004, p. 18)

Is it just a matter of time before the remaining provinces follow suit and chip away at child labour standards? Or, will non-compliance and a lack of enforcement of child labour, from both the state and parents, become the modus operandi? Considering that child labour has historically increased during depressed economic cycles, such as children's mass employment during the Great

Depression and Second World War (Zelizer, 1985), it seems that laws and values may be superseded by, or even temporarily suspended, due to economic considerations.

2.2.2 Social-Cultural

Changes to social values surrounding children’s use value can be seen across a variety of domains. Stalled social norms and practices surrounding unpaid, reproductive labour, the impact of migratory patterns, and changing public discourses surrounding children’s unpaid labour all point to a reconceptualization of children’s usefulness.

2.2.2.1 Stalled gender equality in the division of reproductive labour

Women’s continued participation in the labour market fails to coincide with changing gender norms and practices surrounding unpaid, reproductive labour. For working mothers in particular, the result is an untenable juggling act. Evidence of this is illustrated in a 2012 time-use study conducted by Statistics Canada that compared three generations of young people—the late baby boomers (born 1957 to 1966), Generation X (1967 to 1979) and Generation Y (1980 to 1995). Although there was an increasing similarity in the involvement in paid work and unpaid housework between men and women from the late baby boomers to those in Generation Y, the results varied by familial status. When looking at dual-earner couples, the dominant family form since the 1980s, results showed young adults increasingly share economic and domestic responsibilities. Women’s increases in their hours of paid work were met with a steady increase in their male partners’ share of the housework (Marshall, 2011). When looking at dual-earner couples with *dependent* children, however, women’s contribution to a couple's total paid work time declined amidst their increasing contribution to housework for both Generation X and Y (Marshall, 2011, p. 21). It appears that the rise of a hypothetical ‘househusband’ is limited to childless couples. This adds further credibility to the development of a reproductively useful "housechild" who is increasingly relied upon to fill in some of the reproductive care tasks previously provided by stay-at-home mothers.

2.2.2.2 Changing public conceptions of children's role in reproductive labour

Public conceptions about the role of children in the unpaid household economy are changing. Some discourses point to the moral and developmental value of *children'*s familial contributions and others link the need for children's involvement in work and/or household chores or responsibilities as a way to combat youth problems.

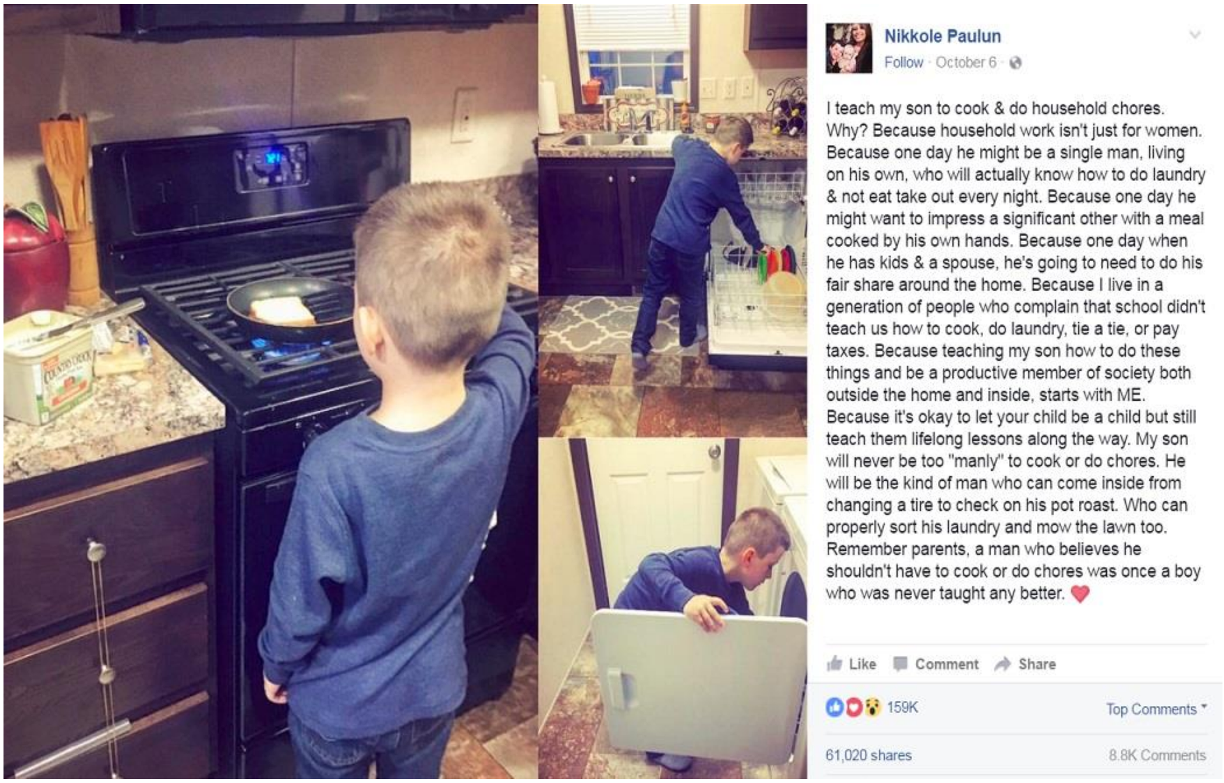
Sociologist Anne-Marie Ambert links children's socially constructed uselessness to increases in youth depression: "It makes life meaningful to children to contribute [in this way] and maybe this is why we have so many kids in high school who feel very depressed, absorbed by Facebook and on smartphone games instead" (Ambert in Boesvled, 2014, Para. 7). Some focus on the disservice parents do for their children when focusing on building scholarly and extracurricular portfolios but fail to prepare them for the one thing they will all have to do in their lives: run a household (Blau in Weikle, 2013).

A rising moral sentiment, embedded in a discourse advocating for more egalitarian divisions of household labour, has also gained momentum. In a six-part *Globe & Mail* series on how families and nations "tackle the chore challenge", the call for parents to make use of the "great, untapped household labour pool: your kids" is increasingly pitched as the new strategy to rectify imbalances in reproductive labour and growing role overload among working parents, especially mothers (Anderssen, 2013, title & headline). One Calgary mother, Jessica Stilwell, made international news by staging a six-day anti-housework "strike" in 2012 as a way to protest the lack of assistance her three daughters (aged 10 to 12) provided to the household economy. Her self-titled experiment first made its way on a personal blog entitled "Crazy Working Mother" –

itself reflective of working mothers' harried lives – before making its way to London's *Daily Telegraph* and the *Today Show* in the United States where she was interviewed by Katie Couric. Not a strict moral debate on the need for children to work as a way to become more civic-minded future adults, Stillwell's actions were of practical consideration to protest the enduring inequality of reproductive labour, historically offloaded onto adult woman. Interestingly, though, the attention was pointed to her daughters and not her husband, evidence of a gendered facet to parents' growing rejection of the "useless" child. One must also wonder whether Stillwell's strike would have been carried out had the household been comprised of three boys versus three girls, who by virtue of their gender should have been better house-children.

Highlighting how familial ideologies impact children's reproductive labour, "16 and Pregnant" U.S reality TV star Nikkole Paulun made international headlines after sharing images of her six-year-old son engaged in a range of household jobs on a Facebook post (Figure 1.1). Shared over 59,000 times and liked over 159,000 times, the post immediately went viral and prompted other parents to share pictures of their sons doing housework. Unlike the scenario with Mrs. Stillwell's three daughters, however, the involvement of a younger boy engaged in traditionally female-typed household work elicited both praise and uproar. While this scenario involved a much younger child, some of the criticism focused not on the age of the child but on the gendered role reversal. As one critique comments: "*You do not have kids to be your slave! Or to do the chores that you yourself don't want to do. I agree with teaching responsibility! But enough is enough*". Another questions whether her stance on gender stereotypes operates both ways "*Will you teach daughters to do yard work, change a tire and mow the lawns or the typical response of that's a man's job only goes one way*?" Compared to Mrs. Stillwell who garnered widespread praise for forcing her daughters to contribute to the household economy, Ms. Paulun's less antagonistic efforts were met with mixed reactions. It appears that familial ideologies impacting mothers' share of reproductive labour trickles down to their daughters before their sons.

Figure 1.1. Facebook post of Nikkole Paulun (October 6, 2016).



Nikkole Paulun
Follow · October 6

I teach my son to cook & do household chores. Why? Because household work isn't just for women. Because one day he might be a single man, living on his own, who will actually know how to do laundry & not eat take out every night. Because one day he might want to impress a significant other with a meal cooked by his own hands. Because one day when he has kids & a spouse, he's going to need to do his fair share around the home. Because I live in a generation of people who complain that school didn't teach us how to cook, do laundry, tie a tie, or pay taxes. Because teaching my son how to do these things and be a productive member of society both outside the home and inside, starts with ME. Because it's okay to let your child be a child but still teach them lifelong lessons along the way. My son will never be too "manly" to cook or do chores. He will be the kind of man who can come inside from changing a tire to check on his pot roast. Who can properly sort his laundry and mow the lawn too. Remember parents, a man who believes he shouldn't have to cook or do chores was once a boy who was never taught any better. ❤

<u>2.2.2.3 Migratory patterns and children's reproductive labour</u>

Migratory patterns further impact practices around children's participation in both unpaid and paid labour. As Zelizer (2004) reveals, children's work is grounded within a web of social relations, the meaning, organization, contribution, and compensation of which varies systematically and dramatically from one social setting to another (Zelizer, 2004, p.3). Looking to the global south illuminates these differences. Children's continued participation in a much wider range of paid work that is often hazardous and exploitative is indicative of the cultural and class-based variations in children's paid work. In Canada, there still exists disparate work trajectories for different classes of children, particularly immigrant children and those from the most economically impoverished households. In 2011, Canada had the highest foreign-born population[13] of the G8 countries with 20.6%, well above Germany with 13% and the United States with 12.9%. The largest source of immigrants is from Asia (including the Middle East) followed by Africa, the Caribbean, and Central and South America (Statistics Canada, 2013a). Data from the 2011 National Household Survey also shows that the majority of Canadians living in low-income neighborhoods are immigrants (36.6%), with nearly half of those being recent immigrants arriving between 2001 and 2010 (Rennie, 2013). Given the relative poverty of many of these recent immigrant families, children's higher level of involvement in unpaid family care work becomes a strategy to cope with financial difficulties.

Building off this last point, Zelizer (1985) demonstrates that the last to sign onto the new social contract of the emotionally priceless but economically useless child were working class and/or immigrant families who either could not afford to forego their children's contributions and/or whose cultures opposed it. Although an initial scan of the Canadian literature reveals no relevant research, ethnographic evidence out of the United States corroborates how cultural variation via changing migration patterns impacts the amount and framing of children's labour. Families emigrating from rural areas in global south countries, for example, often assume that children will contribute to the household economy. As one Guatemalan mother who immigrated to Los Angeles reveals: "You have a family, and if we're a family, we work together" (Thorne, 2012, p.478). Similar patterns exist for immigrant families from Yemen, whose children were observed to work after school and on weekends in the household economy, performing a great deal of childcare and housework (Thorne, 2012). Asian youth have also been shown to play crucial roles in their family-run businesses, often deploying both linguistic skills and manual labour to

---

[13] In 2011, Canada's foreign-born population rested at about 6,775,800 people (Statistics Canada, 2013).

assist in their operation (Song, 1999; Sun-Hee Park, 2002). When interviewed, it becomes clear that many immigrant youth fail to conceptualize their work as labour but tend to see their efforts as merely “helping out” (Zelizer, 2004 p.10). Accounting for the historical, cultural and political-economic specificity of the “economically useless but emotionally priceless” child therefore enables us to better understand the factors that contribute to its destabilization. It also highlights how, despite many sociological studies focusing on ethnic businesses as key “ethnic resources”, we still know very little about children’s participation within them (Song, 1999).

2.2.3 Demographic

Changes in the demographic structure of the Canadian population facilitate additional shifts in the conceptualization of childhood. The ageing Canadian population, amidst increasing longevity and diversity in family types, accelerates the transition away from viewing children as reproductively useless in favour of viewing them as useful once again.

First, increasing life expectancy and decreasing fertility has resulted in the drastic aging of Canada’s population over the last century. By 2036, more than quarter of the Canadian population (10.4 million) will be over the age of 65 (CIHI, 2011). With the vast majority of Canadian seniors (90%) living in private households, the supplementary financial and unpaid care required for older persons to “age in place” is an increasingly challenging task for families (Turcotte & Sawaya in Mandel & Stamatopoulos, 2017). Statistics reveal that Canadian families are starting to take steps to manage the growing need for unpaid senior care privately. One such step involves grandparents moving into households with their adult children and grandchildren. About 8% of all grandparents aged 45 and older (close to 600,000) lived in the same household as their grandchildren in 2011 (Statistics Canada, 2015b). With Canada’s current population of grandparents significantly older than just a quarter-century ago, generational overlap is posed to occur later in life when health concerns are more common (Margolis & Wright, 2017). Moreover, with Canadian parents at work for a longer portion of their lives and in jobs with more variable or non-standard hours, the demands for elder care will potentially fall onto children who are seen as more flexible to provide such care. For the additional 72,700 grandparents aged 45 and older who live in "skip-generation" households (i.e., where no middle-generation is present), it becomes a near inevitability that children will provide added caregiving for their grandparent guardians (Statistics Canada, 2015b). Co-residency aside, there still exists an attendant need to send persons outside of their households to care for the seven million grandparents living in private households.

Second, changing family types also leads to an increased need for, and availability of, child and youth workers. Households and families have shrunk due to declining fertility and the number of lone-parent families has increased due to changing marriage patterns. As a result, the number of private households has continued to grow faster than the population. In Canada, we see this in two sets of dichotomous statistics. First, the average number of children per Canadian family decreased from 2.7 in 1961 to 1.9 in 2011 (Statistics Canada, 2012a, p.2). The average total number of people per family decreased from 3.9 in 1961 to 2.9 in 2011, while the number of lone-parent families doubled since 1961 to constitute 16.3% of all census families in 2011 (Statistics Canada, 2012a, p.2). Second, despite familial and household sizes shrinking, the number of private households has grown faster than the population and has done so since 1961 (Statistics Canada, 2012a, p.4). Whether these patterns are due to declining fertility or rising rates of separation and divorce, the result is the same: an increasing need for unpaid family workers to help assist with the growing level of unpaid work, especially in families where parental illness or disability exists and/or in dual-earner families with unmet child and/or elder care needs.

2.3 DISCUSSION

In *One Nation Divisible: What America Was and What It Is Becoming* (2006), Michael B. Katz and Mark J. Stern argued that during the last decades of the 20th century, changes as profound as those occasioned by the industrial revolution deconstructed dominant ideas of family, work, occupation, race, and nationality and undermined the institutional, economic, and cultural pillars sustaining the priceless child. Would the drop in real global wages since 1973 and the most recent 2008 recession put added pressure on children and youth to become more economically useful and provide financial supports to their families? Would that be reflected in after-school employment? Across Canada, statistics show that labour force participation rates of youth aged 15 to 24 actually declined 3.8 percentage points from 2008 to 2014, increasing only for those workers aged 25 and older (Bernard, 2015). Add that to the documented crises in youth under- and unemployment and the Canadian evidence would seem to refute this supposition. While Katz and Stern (2006) and Katz (2012) are correct in theorizing that youth will become more useful in contemporary society, these authors were simply mistaken as to what *form* this new usefulness would take.

Distinct from Zelizer's demarcation between those 'economically' useless children that reigned in the first period of transition to the modern era and the economically useful children of the pre-modern era, emerging global capitalist-inspired definitions of childhood have taken on a key *unpaid and reproductive* quality. Given that children have retained their emotional and/or priceless quality into the present, it is unlikely that a resurrection of the pre-modern, undifferentiated child – who laboured and leisured much the same as adults – will occur within the near future. Instead, and in line with Zelizer's prediction almost 30 years ago, we are witnessing a serious re-evaluation of children's instrumental worth with the emergence of the new "housechild" (Zelizer, 1985, p.223).

Solberg’s decade-long research on the everyday lives of Norwegian children corroborates this contention, noting how women’s mass exit out of the household and into paid work led to mothers and children switching roles. Children invaded the home as their mothers invaded the labour market (Solberg in James & Prout, 1997). Using a multimethod research design consisting of qualitative fieldwork supplemented with Norwegian time-use data over 1980 to 1990, Solberg shows how the proportions of children and adults carrying out various household activities during a given day are surprisingly similar (Solberg in James & Prout, 1997). Moreover, gender differences in the traditional division of labour between men and women were also found to apply to children, with daughters engaging in much more household labour than sons (Solberg in James & Prout, 1997).

To be sure, adult women continue to perform the majority of reproductive labour and children from wealthier families continue to enjoy a predominantly useless existence. Economically and reproductively useful children tend to be from low-income families. Rina Cohen’s (2001) cross-cultural analysis of children's household labour in three socio-cultural contexts – a village in Southern India, a small town in Norway and an urban Canadian city – reiterates the structural necessity of children’s domestic labour. Cohen reveals that while children’s household production has always been a structural necessity for the maintenance of rural households, it has become increasingly necessary for the maintenance of urban-industrial households over the past three decades. The changing worth, or value, of children's contribution to domestic labour is primarily linked to family resources: the fewer the resources, the higher the value of children's contribution (Cohen, 2001). She also concludes that gender matters, with girls consistently contributing more household labour than boys. Dodson and Dickert’s (2004) decade of qualitative research corroborates the necessity of low-income families to maximize their children's reproductive labour. By employing rich triangulated qualitative data over a 10-year period, Dodson and Dickert highlight the often overlooked pattern of girls' family labour as a critical source of support for many low-income families in the United States. By examining respondents' understanding of children's work, they reveal how households with low wages and absent adult caregivers result in children, often girls, providing essential, complex, and time-consuming family labour. Dodson and Dickert conclude that although researchers have examined children's household work, largely in the context of whether doing chores benefits children, the use of children to provide critical family care labour is absent from most work and family scholarship (Dodson & Dickert 2004, p.318).

Where we do locate a greater subset of findings pertaining to children's reproductive labour is in the global young carer literature. Here, youth's substantial unpaid care work for family members with a chronic illness or disability has been well documented for over two decades. Problematically though, its predominant concentration on youth providing care for a "dependent" relative excludes additional child family labourers motivated by economic necessity and perpetuates dubious distinctions between qualifying and non-qualifying forms of children's care work (Olsen in Zelizer 2004, p. 6). In this dissertation, I amalgamate *young carer* literature with that of the *work and family* literature. Extending the discourse surrounding children's labour to include caregiving motivated not only by chronic familial illness or disability but also by practical and financial necessity reveals how the social reproduction of households has become a variegated and nuanced phenomenon.

Furthermore, supplementing a feminist political framework with a socio-historical review of norms surrounding childhood, especially acceptable norms of child labour, helps us understand why young carers have gained attention as a special category of discourse and policy development in contemporary global capitalist society. Interesting parallels exist between the current move towards more useful childhoods and the previous era's movement away from useful childhoods. Zelizer revealed to us the ideological conflict over child labour that occurred between *reformers* in favour of banning child labour and the equally vehement *anti-reformers* who argued for labour's positive role in children's lives during the modern-day era of childhood (Zelizer, 1985, p. 57). Today, an equally contentious debate exists within the young carer movement between young carer proponents (i.e. the postmodern day equivalent of the 'reformers') and their opponents (i.e., the postmodern 'anti-reformers'). The former push for dedicated supports and the ultimate prevention of young people's caring roles while the latter oppose state-based intervention and/or the pathological depiction of children's reproductive care labour.

Of those belonging to the former, we find the largely successful U.K. based young carer advocates who highlight the harmful impact of children's ongoing and substantial caring roles. This camp has been successful in securing legal rights and substantial formal funding dedicated to young carer programming and prevention (Aldridge & Becker, 1993; 1997; Dearden & Becker, 1997; Frank, 1995). The opponents include those disability scholars who were among the first to reveal the social constructionist nature of the phenomenon of 'young carers' (Keith & Morris, 1995, p.37). Their objections are not historically grounded within discourses documenting the larger changes to childhood. Instead, they focus on the way non-disabled feminist and young carer researchers define family members and friends who provide help to older and disabled people as "carers" and those they care for as "dependents" (Keith & Morris, 1995, p.37). The young carers movement is thus criticized for detracting attention and public services away from the person requiring care, as well as for the suggestion that all children's care for a disabled or ill parent is harmful (Morris, 1997).

Childhood scholars also note the social constructionist nature of the “young carer” label itself. Olsen (2000) reveals how the ‘young carer’ label holds important implications worth keeping in mind. These include: (1) the implication that this group of children has existed for generations and has only now been ‘discovered’ by researchers and campaigners; (2) the tendency to label particular types or quantities of work as harmful or beneficial to children which also serves to exclude some segments of reproductively useful children from eligibility and, (3) the absent historical dimension of what constitutes an appropriate involvement in domestic and care work on the part of children (Olsen, 2000, p. 391). Olsen (2000) accurately notes that the predominant focus, by young carer and disability rights scholars alike, on how to best support such families’ caregivers and care-receivers has occurred without any attempt to locate such debates within a broader historical and/or sociological paradigm.

This analysis sought to reveal how the ever-changing conceptualization of “childhood” occurs in historical conjunction with wider pan-societal structural change. Young carers as a collective provide a key piece of evidence for the emerging emotionally priceless *and* reproductively useful childhood triggered by new economic structures ushered in by global capitalism. Shifting definitions around “childhood” raise additional questions about the implications this has for children’s life course trajectories, particularly as it relates to their future economic and emotional well-being. For example, does the uptake of added reproductive labour endanger children’s educational and future economic security? Does it pose benefits that are advantageous to the child? Or, as Dodson & Dickert (2004) conclude in their research among low-income children providing substantial family labour in the United States, does it primarily result in less time spent on school and extracurricular activities that amounts to “profound opportunity costs and foregone and forgotten dreams” (Dodson & Dickert, 2004, p. 319). Finally, what are the avenues of support presently available to caregiving youth in Canada and what is needed going forward to address the risks of added child-based reproductive (care) labour? The remainder of this dissertation will explore such questions by focusing on the phenomenon of youth-based caregiving within Canada – ultimately assessing the degree to which the modern era's emotionally priceless but economically useless child is one we can no longer afford to sustain.

CHAPTER THREE

Research Design: A Multimethod Approach to Studying Young Carers.

This chapter provides an overview of this study's methods and methodology. To begin, a brief discussion of the key rationale for the multimethod approach will lead into a summary of its overarching research objectives and underlying epistemological and ontological considerations. Next, the quantitative and qualitative portions of the design will be broken down into their constituent parts, including a discussion of their rationales, recruitment strategies, data collection and analysis techniques, and subsequent limitations. A final section will provide a post-hoc reflection of the project as a whole that illuminates both unanticipated challenges and offers recommendations for follow-up research.

3.1 THE CASE FOR A MULTIMETHOD APPROACH

Taking its name from Campbell and Fiske's famous 1959 article on measurement validation, *multimethod* research involves the conscious and systematic strategy of combining different styles or methods within the same research project as a way of providing increased power of persuasion and strengthened claims to validity (Brewer & Hunter, 1989, 2006). Researchers have long been conducting multimethod research but often under a variety of classificatory labels, including "mixed methods", "integrated," "hybrid", "combined" or "multimethod" research. Indeed, the variety of terms employed by researchers and the often slightly different meanings attached to them, have been a source of confusion in the literature (Byrne & Humble, 2007). Most commonly the confusion surrounds the difference between multiple/multimethod and mixed methods designs. In the Handbook of *Mixed Methods in Social & Behavioural Science*, Creswell, Plano and Clark

(2007) help differentiate between the two. Mixed methods designs can be divided into two categories, with “mixed model” designs bringing together both qualitative and quantitative projects in more than one stage of the study and “mixed methods” designs which involve the collection or analysis of both types of data in a single study (Teddlie & Tashakkori, 2003). As an example, a researcher who conducts surveys with a large group of individuals in one stage of the study but then conducts in-depth interviews with a sub-sample of those individuals would be using a mixed model design. A researcher who executes a survey comprised primarily of both closed-ended questions but includes a handful of open-ended questions that build off some of the closed-ended questions would be using a mixed methods design. Multimethod designs are different from mixed methods designs in that the qualitative and quantitative studies are relatively complete on their own and are used together to form essential components of one larger study or program. In this sense, each smaller study is planned and executed to answer particular sub-questions that together can be triangulated to form a comprehensive whole (Morse, 2003). This dissertation fits most closely with the definition of multimethod research in that each of the three research objectives seeks to answer specific sub-questions related to: (1) the prevalence of youth-based caregiving (quantitative) located in Chapter Four, (2) the practice of youth-based caregiving (qualitative) located in Chapter Five, and (3) the policy surrounding youth-based caregiving (qualitative) located in Chapter Six. Moreover, two popular multimethod strategies will be employed: “Sequential” procedures that seek to elaborate and expand upon the findings of one method with another method and “Concurrent” procedures that aim to converge quantitative and qualitative data in one study in order to integrate the information in the interpretation of the overall results (Creswell, 2003, p. 16).

Irrespective of terminological and operational variation, the overriding goal of these designs is the same – to expand the breadth of research by offsetting weaknesses of either approach alone (Blake, 1989; Bryman, 2006; Creswell & Plano, Clark, 2007; Driscoll, Appiah-Yeboah, Salib & Rupert, 2007). My decision to combine qualitative and quantitative techniques was thus important for four reasons. First, since qualitative techniques are ideal for exploratory analyses, they are particularly well suited to this study given the established scarcity of Canadian scholarship in this area. Second, qualitative methods are best able to build upon the felt needs and lived experiences of young carers and the frontline staff supporting them. The inclusion of quantitative data served a third goal of providing the macro-level aggregate patterning of youth-based caregiving currently absent from the Canadian literature and unavailable from smaller-scale qualitative studies. Fourth and last, triangulating different data sets and combining methods within sub-studies provides an opportunity to assess the usefulness of each data collection technique against the other. For example, I was able to evaluate the utility of pre-existing (secondary) data sources against my emerging qualitative data to assess the degree to which pre-constructed survey instruments sufficiently tapped into (and subsequently enumerated) all those potential young carers. I was also able to cross-reference my focus group interview data with the short accompanying post-focus group survey data to flush out how continuity or change between the two sets of responses potentially reflected the added confidentiality provided by the survey format. Consequently, the combination of multiple methods provided a more comprehensive view of youth-based caregiving that addressed both its individual (micro-level) and national (macro-level) process and patterning.

3.2. PROJECT OBJECTIVES AND EPISTEMOLOGICAL CONSIDERATIONS

With the scarcity of Canadian empirical research in the area, the key purpose of this dissertation was to fill in specific gaps that I deemed most pressing. Accordingly, three general objectives of this study included: assessing the prevalence of young carers across Canada; exploring the national supports available to support youth in their caregiving roles and, providing a first-hand account of youth-based caregiving from the perspective of youth themselves. In addition to these overarching objectives, eight separate and more targeted research questions were included for empirical investigation:

1. How many youths provide unpaid caregiving across Canada?
2. Are there any gender or age differentiated patterns to youth-based caregiving?
3. What level and types of care work do youth provide?
4. What supports are available to youth caregivers across Canada?
5. What are the challenges to increasing the scope and reach of current young carer programming?
6. How do youth explain their involvement in caregiving?
7. How do youth balance their caregiving with other responsibilities (e.g., social, educational and professional?)
8. What are the consequences (e.g. social, emotional, physical, and educational) for youth involved in caregiving?

Accompanied by each research objective are underlying assumptions regarding what constitutes valid knowledge and how to go about obtaining it (i.e., epistemology) as well as what constitutes reality (ontology), both of which are part of a broader model or paradigm. Different paradigms inherently contain divergent, sometimes oppositional, views regarding which data collection and analysis techniques will best capture a given social reality. As such, decisions surrounding methodology – the strategy or plan of action behind the choice and use of particular methods – and the specific techniques and procedures (methods) used will naturally vary by paradigm (Crotty, 1998, p. 3).

The questions borne out of the first research objective approach youth-based caregiving as something that can be measured numerically using reliable, verifiable, and precise testing instruments. In this case, the very nature of these research questions presuppose the choice of methods utilized, with quantitative analyses of existing secondary data the only feasible option for providing such Canada-wide prevalence estimates. Nevertheless, the very ontological assumption that social reality is something independent of our observations or knowledge, comprised of social facts to be collected and analyzed systematically using scientific, value-free, precise, quantifiable, and replicable methods is in line with a *positivist* paradigm (Neuman & Robson, 2012).

Most ardently and successfully pushed forward by August Comte in the mid-19th century, researchers from the positivist camp argue that the social world operates similar to the physical world (according to absolute laws) with a subsequent epistemic prioritization for knowledge that can be validated by empirical observation (Durand & Vaara, 2006). In line with these assumptions, researchers tend to choose methodologies that revolve around empiricism, with a focus on corresponding measures and estimation models that emphasize quantification, prediction, replication and causality. Quantitative methods that emphasize objective measurements and the statistical, mathematical, or numerical analysis of data collected through experimentation, surveys or the analyses of pre-existing data tend to be preferred methods for positivist researchers. While such measurement techniques may be an important first step in identifying patterns of behaviour and trends, combining different kinds of research methods provides a more complete and nuanced understanding of these patterns and trends.

The awareness of this fact, and the larger limits to positivism, were first formulated by German sociologists Max Weber and Georg Simmel when launching the *Interpretivist* countermovement. By denouncing the application of strict scientific principles or scientism to the investigation of social phenomena (Rhoads, 2010), these and other anti-positivist researchers argued against merely describing, controlling and predicting social phenomena in favour of *understanding* them via the process of Verstehen[14]. Advanced most successfully by the "Chicago school"[15] during the 1920's – 1930's, the interpretivist movement gained traction for the richness its methods (e.g., ethnographies, in-depth interviews) brought to describing social phenomena but also capturing the meanings and motives behind people's actions. To interpretivists and other critical epistemologists, there is no singular reality that is objectively experienced by all; instead, reality is fluid, relative and comprised of multiple sets of realities that depend on other systems for meanings (Lincoln & Guba, 1982; Neuman, 2000). This ontological assumption coexists with the epistemological rejection of any so-called *value-free* research since the way the social world is understood and studied is never independent of one's own biases, subjectivity and taken-for-granted assumptions. These epistemological and ontological standpoints coincide with divergent methodological preferences, the reasons for which will be expanded upon as they relate to two key themes: reduction and detachment.

First, the desire to study limited but large-scale phenomena results in the reduction of data collection to a limited set of fragmented and pre-determined areas. Survey researchers assessing complex social issues, such as caregiving, who attempt to capture its intricacy with limited questions offering pre-determined response options, are inherently making a trade-off between

---

[14] Verstehen is a German term loosely defined as 'empathetic understanding' that entails reliving the experience of the actor or at least rethinking the actor's thoughts (Martin, 2000, p. 1).

[15] Refers to the specific group of sociologists at the University of Chicago who were pioneers of qualitative research methods of social investigation (Scannell, 2007, p.10).

breadth and depth for greater sample sizes and faster analytic turnaround. This reductionist tendency to turn complex processes into simplified and stylized representations specific to pre-determined research questions or hypotheses prevents all aspects of a problem from being covered (Quade, 1970). Moreover, with sensitive social issues there is risk of offending or alienating respondents by limiting their responses with possibly inappropriate or cold survey questions, adding to the more well-known error sources pertaining to artificiality (especially in the case of experimental designs) and broader issues with survey question comprehension, social desirability bias and memory recall in the case of survey research. Finally, there exist issues of incompatibility when using any sources of secondary data, primarily in the way initial researchers may have conceptualized and operationalized the included variables. Notwithstanding these concerns, the use of national survey data is the only option for acquiring national prevalence estimates, even though it does so at costs pertaining to instrument and sampling decisions that reflect adult-centric biases (to be discussed in the next section).

Second, the positivist tradition's "want of objectivity" (Hirsh & Olsen, 1995, p. 193) and its insistence on a detached and distanced relationship between the researcher and his/her subject (in order to retain an emotional neutrality) can work against the collection of truthful data in two ways. In line with critical feminist scholars Sandra Harding (2004) and Dorothy Smith (1987), it has led to the historical exclusion of many marginalized groups from the production of knowledge that in turn facilitates a distorted representation of many phenomena. By highlighting how mainstream epistemology has masked relations of power which generate and shape knowledge, critical feminist scholars have revealed how the disinterested and objective 'knower' has historically been a very particular, specific, and interested knower representing the concerns of privileged white males (Code, 1991). Subsequently, "standpoint" epistemologies – most fully articulated by Dorothy Smith – start from marginalized lives in order to present the world from particular socially situated perspectives (Doucet & Mauthner, 2006; Smith, 1987). For these decisions, it was crucial that the final two research objectives began from the standpoint of young carers and those social service professionals assisting them in order to correct for the adult-centric bias in existing care literature. Positivist methods of collecting data and their underlying assumptions surrounding neutral detachment can also produce discomfort among certain respondents, with one study showing that family caregivers are often uncomfortable with survey terminology designating family members as *caregivers* (Lake Snell Perry & Associates, 2001). This relates to the larger dilemma of developing rapport with subjects that is particularly important when studying more personal and highly nuanced issues, such as familial caregiving, and when doing so with vulnerable and/or hidden child and youth populations. I would argue that my role as researcher *and* previous young adult carer helped not only to break down power differentials between myself and my subjects but also to promote a greater sense of trust that was largely a result of our shared standpoint/positionality.

It is this appreciation of the strengths and limitations of both positivist and anti-positivist/interpretivist epistemologies that guides my decision to undertake a multimethod approach, selecting a combination of quantitative and qualitative methodologies as distinct and beneficial when used in a complementary and/or mutually supportive fashion.

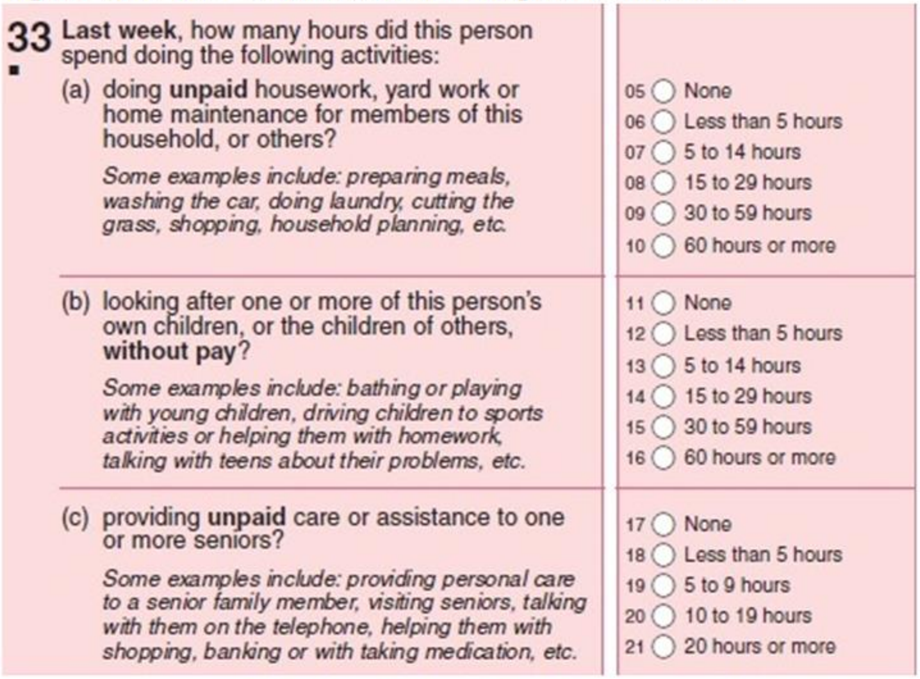
3.3 QUANTITATIVE STUDY

First, Canadian census data is used to map the incidence of youth-based caregiving across Canada. This descriptive analysis of youth-based caregiving over time is crucial given that available national datasets have yet to be analyzed – a point reiterated by a recent Action Canada Task Force on Young Carers (Action Canada Task Force, 2013). Second, the recent release of the 26th cycle of the General Social Survey dedicated to "Caregiving and Care Receiving" provides me with a previously nonexistent opportunity to analyze the issue in greater depth than afforded by the census.

3.3.1. Quantitative data sources

The census provides a statistical portrait of the Canadian country and its people on one specific day and includes a short and long-form component. Four out of five households (80%) receive the short-form census questionnaire containing six questions of a demographic and linguistic nature. The remaining one in five households (20%) receive the long-form census questionnaire containing the eight questions from the short form plus an additional 53 questions on topics such as education, ethnicity, mobility, income, and caregiving (Statistics Canada, 2006a). Two cycles of Canadian long-form census data (1996 and 2006) will be used to explore the incidence of youth-based caregiving across Canada, its regional variation and the age and gender-based differentiation to the types and level of care provided by youth aged 15 to 24. These cycles are selected since they cover the full range of years for which the "Unpaid Work" module was included in the long-form census before being removed in 2011. The full module can be seen in Figure 3.1, with only sub-questions (b) and (c) included in the analysis as they pertain to care and support provided to other persons. Public use microdata files (PUMF's) were used for analysis, containing roughly 2.7% of the total population and amounting to sample sizes of 792,448 in 1996 and 844,476 in 2006 (Statistics Canada, 1996, 2001, 2006). The introduction of the 2011 National Household Survey (NHS) – a shorter, voluntary version of the previously mandatory long-form census, saw the elimination of the unpaid work module from its newly streamlined version. While there was widespread uproar with the changes made to the 2011 NHS, most of the attention was paid to its new *voluntary* nature. Moreover, despite the recently elected Liberal government's reinstatement of its mandatory component, the unpaid work module remained excluded from the 2016 long-form questionnaire.

Figure 3.1. 2006 Census module on unpaid wok (Q.33)



33 **Last week**, how many hours did this person spend doing the following activities:

(a) doing **unpaid** housework, yard work or home maintenance for members of this household, or others?

Some examples include: preparing meals, washing the car, doing laundry, cutting the grass, shopping, household planning, etc.

05 ○ None
06 ○ Less than 5 hours
07 ○ 5 to 14 hours
08 ○ 15 to 29 hours
09 ○ 30 to 59 hours
10 ○ 60 hours or more

(b) looking after one or more of this person's own children, or the children of others, **without pay**?

Some examples include: bathing or playing with young children, driving children to sports activities or helping them with homework, talking with teens about their problems, etc.

11 ○ None
12 ○ Less than 5 hours
13 ○ 5 to 14 hours
14 ○ 15 to 29 hours
15 ○ 30 to 59 hours
16 ○ 60 hours or more

(c) providing **unpaid** care or assistance to one or more seniors?

Some examples include: providing personal care to a senior family member, visiting seniors, talking with them on the telephone, helping them with shopping, banking or with taking medication, etc.

17 ○ None
18 ○ Less than 5 hours
19 ○ 5 to 9 hours
20 ○ 10 to 19 hours
21 ○ 20 hours or more

Source: Statistics Canada. (2006). Long Form Census Questionnaire.

This leaves us with the 2006 census data as the most recent nationally representative survey data on unpaid work across Canada. Interestingly, the only questions removed from the 2011 NHS under the directive of the Harper Government were those pertaining to unpaid work, the result of which was declared by Kathleen Lahey, a law professor at Queen's University, as the government's decision to erase the care economy (Scoffield, 2010). In fact, the initial inclusion of unpaid care questions in the census resulted from the efforts of many women's groups, who in the 1990s, engaged in sustained and multi-faceted attempts to challenge statisticians on the notion that only paid labour contributes to production (Luxton & Vosko, 1998). These same women's groups were the first to challenge the Harper Government on the omission of the unpaid work module from the 2011 census. The most forceful response came from the *Status of Women Canada*, which filed a motion in February 2011 with the House of Commons (30th Parliament, 3rd session) demanding that not only the questions be reinstated but that a comprehensive public consultation be commissioned on the possibility of expanding the unpaid work module for the 2016 long-form census (House of Commons Canada, 2011).

When inquiring as to their continued absence in the recently administered 2016 census, I was informed that the 2012 General Social Survey (GSS) dedicated to "Caregiving and Care Receiving" was a large part of that decision[16]. Designed as a series of independent, annual, cross-sectional surveys, the GSS was launched in 1985 with the goal of monitoring changes in living conditions of Canadians along six key themes: caregiving, families, time use, social identity, volunteering and victimization (Statistics Canada, 2013c). Each of the themes is repeated every five years with new topics and questions added to subsequent cycle surveys as deemed necessary in order to address emerging, policy-relevant issues. The 2012 cycle repeated the caregiving theme by collecting data on the situation of Canadians who provide or receive help or care because of a long-term health condition, a disability or problems related to aging. In order to reach more care receivers, a special *rejective sampling* technique was employed in order to include more respondents from this admittedly "hard-to-reach" population (Statistics Canada, 2012b, p.7). Rejective sampling works by 'rejecting' a certain portion of the population with a given probability in order to allow more time and effort to be spent trying to find the population of interest, in this case caregivers and care receivers. As Statistics Canada elaborates:

> This rejective sampling technique is analogous to sub-sampling, except that rather than viewing it as subsampling a portion of respondents (i.e. those not 'rejected') it is viewed contrarily as 'rejecting' a portion of the respondents (i.e. all those not sub-sampled). By rejecting a portion

---

[16] The other rationales included a presumed lack of interest from researchers in using this data in addition to the questions being too vague in nature to be of any solid use.

> of respondents, it allows for more call attempts to be made, possibly increasing the number of care receivers found. It should be pointed out that, because caregivers are more prevalent in the population, they are much easier to find than care receivers. (2013, p.7)

In this method, a respondent was first classified as a caregiver, care receiver, both or neither with a second stage of sub-sampling then carried out for selected respondents who are neither caregivers nor care receivers. All respondents who cited being a caregiver or care receiver completed a long interview and those who were neither caregivers nor care receivers were randomly divided into two groups, with one group completing a long interview and the other completing a short interview. A total of 25,000 respondents completed a long interview for the main survey and an additional 11,500 respondents completed a short interview. Although all of the respondents interviewed are considered respondents, a total of 13,047 rejected cases were removed from the PUMF with their information only used to assist with the weighting process. The resulting sample size of 23,093 thus represents all of those non-institutionalized persons 15 years of age or older who lived in the ten provinces of Canada. The overall response rate was 65.7% (Statistics Canada, 2012b).

Unlike the unpaid work questions in the census, however, the GSS questions provide a qualifier akin to the U.K. and Australian censuses which stipulates that care must be provided due to "long-term illness, disability or aging", rendering the findings more conceptually valid with those from the United Kingdom and Australia. By the same token it also renders the GSS data less conceptually valid against the Canadian census data which arguably collects data from potentially different groups of young carers. Specifically, the census likely underestimates child and youth-based caregiving provided in the context of chronic mental or physical illness or disability while overestimating sibling care resulting from parental absence or incapacity – arguably linked to familial fragility and the rising need for dual-earner households. Notwithstanding this limitation, information from the GSS can nuance census prevalence statistics by providing added detail unavailable from the aforementioned census module on unpaid work, including details about the nature of the relationship between caregiver and care receiver (i.e., are the two relatives, neighbours, friends, etc.) and the different types of care provided by youth (e.g., transportation, meal preparation, banking etc.).

3.3.2 Limitations of data sources

While the census represents the best source of nationally representative data on young carers aged 15–24 years in Canada, there exist conceptual and operational issues that substantially undercount the actual number of young carers in Canada.

First, the failure to probe unpaid care provided to *adults* leaves out all those young carers who have been shown in the global literature to provide care for a parent with a long-term illness or disability (Aldridge & Becker, 1993; Becker, 2007; Becker & Becker, 2008; Cass et al., 2009; Frank, 1995).

A second error of omission involves the restriction of the eligible respondent universe to youth aged 15 years or older, effectively eliminating half of the prospective universe of young carers aged 5–14. These two errors prevent meaningful comparisons to be made between countries on the incidence of young caring due to their differences in defining and enumerating younger caregivers. For example, the U.K. and Australian censuses count care provided to *all* individuals (not simply children and seniors) with the U.K. census going a step further by enumerating care provided by youth of *all* ages. Add to this the U.K. and Australian census-based qualifier that care must be provided in the context of disability, a long-term illness or problems related to old age and the census data becomes even less comparable.

A third but largely operational constraint relates to the qualifying time-period for which respondents were to report their caregiving duties. The census limits the reporting of care to only that provided during the preceding *seven* days. Doing so excludes any young carers providing ongoing support to a sibling or senior with intermittent needs, often the case of people with mental illness, health problems or disability that have sporadic needs for assistance. A strength of the GSS caregiver qualification questions, on the other hand, is that they expand the qualifying time period to the last 12 months.

Finally, and relevant to both datasets, the collection of unpaid work data involves the heightened potential for underreporting on three fronts: first, from parents who may be answering the questions on behalf of their children (parental self-reporting); second, from young carers themselves who may underreport the actual level of care for reasons related to stigma (of chief concern among families impacted by substance abuse or HIV/AIDS) or fear of parental reprisal and/or social service intervention (Aldridge & Becker, 1994; Becker, 2007; Cass et al., 2009) and third, from the broader under-reporting of care tasks due to a failure to view such work as anything outside of the 'normal exchanges of family life' (Walker, Pratt & Eddy, 1995).

For the GSS data, key limitations relate to the sampling frame, eligible respondent universe and resultant sample size. First, the data fail to capture respondents living in Northern Canada (i.e., Yukon and the Northwest Territories) rendering it ineligible as a substitute for the census to provide national estimates. Second, and similar to the census, its decision to enumerate only those individuals aged 15 years and older leaves out the majority of the child caregivers from its sample.

Third and last, there are issues to consider regarding representativeness and bias, largely connected to the voluntary nature of the GSS and the exclusion of cell-phone only households from landline only random digit dialing (RDD) samples. Declining response rates caused by a vanishing culture of survey cooperation represents one of the most serious issues preventing wider generalizability of recent and future surveys (Ornstein 2013). Many factors impact the declining survey culture, including the barrage of telemarketers and less reputable survey requests, increased privacy and security concerns, lifestyle changes that make people more difficult to reach, and changing attitudes towards requests from strangers (Ornstein 2013). To illustrate, Statistics Canada's inaugural GSS (1985) had a response rate of 83.4% (Statistics Canada, 2013c). Cycle 26 (2012) had a response rate of 65.7%. How much will the response rate drop over the next decade? Two decades? Such declines raise concerns for the ability to use forthcoming GSS surveys as a benchmark for comparability against earlier cycles or related datasets.

The exclusion of cell-phone only households from the GSS sampling frame is the second key factor limiting representativeness of youth-centered data. Up until this 26th cycle of the GSS, interviews were conducted by telephone to landline-only households. Based on the most recent Residential Telephone Services Survey (RTSS), conducted in 2013, cell-phone only households represent approximately 21% of the Canadian population (Statistics Canada, 2013b). Although Cycle 26 of GSS attempted to adjust for this undercoverage by weighting its survey estimates to account for both those households without a phone as well as those cell-phone only households, the rapid growth of cell-phone population and their distinctive characteristics suggest it is important to include cell-phone samples going forward (Lee, Brick, Brown & Grant, 2010). Indeed, Statistics Canada has begun redesigning its sampling frame to account for these issues, by replacing the previous RDD sampling frame with one constructed using the address register and other sources of telephone numbers (including cellphone number lists) accessible to Statistics Canada. They are also developing an internet questionnaire to supplement the existing telephone mode of collection (Statistics Canada, 2013c). These changes will come into effect with the subsequent 27th cycle of the GSS (2013) focused on Social Identity. The jury is still out as to how much these changes will improve response rates more generally, but it is expected that these adjustments will ease some of the difficulties in reaching younger, single and urban youth who are the most likely to be cell phone-only users (Statistics Canada, 2013b). It is also hoped that the internet options will further improve coverage of younger respondents while simultaneously helping to stabilize or increase the currently declining GSS response rates (Statistics Canada, 2013c).

3.4 QUALITATIVE STUDY

3.4.1 Young Carer Program Staff Interviews

Interviews were conducted with staff members of young carer programs in order to explore the origins of their respective programs, the range of services offered and the barriers to improving their respective scope and reach. A qualitative interview approach was the ideal method to explore this dissertation's second research objective due to the relative absence of domestic scholarship in the area. As it stands, Chalmers 2011 single-site evaluation the Niagara-based *Powerhouse Project: Young Carers Initiative* represents the sole study looking at dedicated young carer programming. Qualitative interviews are also well suited to discovering the first-hand experiences of those working in the field by enabling informants to "describe their actions, experiences, beliefs, and values as they view them, without being limited to the investigators' predetermined concepts, theories, and questions, as with a survey" (Parker et al., 2009, p. 232). Subsequently, careful effort was made to derive as many detailed descriptions as possible while retaining the personal narratives of those interviewed so not to distort the lived experiences of the participants.

Participants were recruited using purposive "stakeholder" sampling[17] (Palys, 2008) of frontline staff who either launched or currently managed one of the three Canadian young carer programs. Choosing these staffers was an ideal starting point for reviewing both the current range of young carer services available while gaining in-house expertise as to what is needed for their respective improvement and/or growth. Given that this study represents the first review of existing young carer programs in Canada, questions were primarily exploratory in nature and were revised after each interview to account for important areas emerging through ongoing discussion. Areas that were probed included the services offered by the programs, their cumulative reach and current user base as well as any constraints and challenges pertaining to program funding and future goals. The full list of questions can be found in Appendix A.

A total of five current and previous frontline staffers at each of the three existing young carer programs across Canada were interviewed over the telephone (for the three Toronto/Niagara participants) and Skype (for the two Vancouver participants) representing almost half of the combined program employee population of 11. Interviews lasted roughly 75 minutes and were conducted between January 12th and 23rd, 2015. Each interview was recorded with the participants' consent and transcribed in full for subsequent analysis.

The conditions of the consent form were explained verbally over the telephone, which included: 1) full confidentiality, 2) the right to decline to answer any particular question or to end the interview at any point, 3) the right to withdraw from the study at any point and have their data immediately destroyed wherever possible 4) the recording and transcribing of the interviews, and 5) that all interview data would be kept in a secured location (e.g., locked office, password

---

[17] Stakeholder Sampling is a non-probability sampling technique that is particularly useful in the context of evaluation research and policy analysis and involves identifying who the major stakeholders are who are involved in designing, giving, receiving, or administering the program or service being evaluated, and who might otherwise be affected by it (Palys, 2008).

protected digital file) and destroyed after five years. No funding was received to carry out this research and ethics approval was sought and approved by York University's Office of Research Ethics.

After each interview was complete, the process of transcription and subsequent contextual (looking at the data as a whole) and categorical (organizing the data into coded data by ideas or themes) analysis took place. Reflective of the iterative nature of exploratory qualitative research, the series of question-and-answer cycles were also slightly modified with each subsequent interview to factor in emerging themes discovered throughout the interview process. This process was further helped along by the decision to begin transcription immediately after each interview, with the data and emerging patterns and themes still fresh in my mind for follow-up during successive interviews.

The initial phase of contextual coding involved using an approach advocated by Hammersley and Atkinson (1983) that involved immersing myself into the data and then searching out general patterns, theoretically expected findings as well as divergent or inconsistent views offered by participants. Doing so involved a first phase of re-listening of the audio interviews in order to make initial analytic notes and theoretical memos that came to mind. Then I proceeded to analyze the transcribed text, highlighting areas of interest and making notes that factored in the analytic memos made during the previous stage. This positioned me to enter the second phase of categorical analysis whereby the creation of codes[18] occurred through careful attention paid to repetitions of incidents or words, irregularities, unusual occurrences, how people said things (e.g., if responses are followed by droll laughter or angered tone) as well as nonverbal gestures (e.g., long pauses, sighs etc.) (Woods, 1986). Together, an exhaustive list of codes was amassed over

---

[18] A code in qualitative inquiry is most often a word or short phrase that symbolically assigns a summative, salient, essence-capturing, and/or evocative attribute for a portion of language-based or visual data (Saldana, 2008, p.3).

four separate coding sessions spanning a 96-hour period. This iterative nature of coding is not unusual given coding is known to be a characteristically cyclical act, explained well by Saldana (2008):

> Rarely is the first cycle of coding data perfectly attempted. The second cycle (and possibly the third and fourth, and so on) of recoding further manages, filters, highlights, and focuses the salient features of the qualitative data record for generating categories, themes, and concepts, grasping meaning, and/or building theory (p.8).

Once the full list of codes was drafted, a subsequent process of re-examining the full range of themes and concepts occurred, paying attention to how they systematically interrelated. The cumulative process of qualitative data analysis can be well understood using Charmaz's (2006) metaphor where "coding generates the bones of your analysis while integration will assemble those bones into a working skeleton" (p. 45).

While close to half of the current combined program staff was interviewed, the final sample pool of five participants alongside the range of participants selected (i.e., directors and managers) poses a limitation of the study. Future research can provide a more formal evaluation of programming by adding additional perspectives from a wider range of staff, program users (past and present), volunteers and other relevant stakeholders.

3.4.2 Young Carer Interviews

A qualitative focus group design was chosen to explore the lived realities of young people providing unpaid familial caregiving, touching upon such areas as the perceived benefits and penalties of caregiving in addition to the types and level of caregiving provided within their families. Importantly, it provided Canadian youth an opportunity to have their voices heard and share their experiences with caregiving. With the only two existing first-hand accounts of children's caregiving in Canada presenting a localized perspective as it pertains to two distinct illnesses, Multiple Sclerosis and Frontotemporal dementia (FTD), it was necessary to draw in participants providing care in a wider range of contexts. For this study, participants were included in the sample if they provided familial caregiving in any and all contexts, with the only stipulation being that they were within the age range of 15 to 19 years and had been providing a minimum of five hours of care per week (on average) for a minimum of one year. Finally, participants were selected using purposive sampling (i.e., non-probability sampling technique also known as judgmental or selective) from existing young carer programs, a preferred design method for five reasons.

First, with the process of finding young carers documented to be a complex and difficult one (Eley, 2004; Segal & Simpkins, 1993; Tucker & Liddiard, 1999), a purposive sampling strategy using two of the three existing non-profit organizations currently providing dedicated young carer services was the most efficient method of locating eligible youth. Site selection was based on geographical proximity to the interviewer (i.e., myself).

Second, coordinating research with young carer program staff and using known program locations with which to conduct the interviews (i.e. the Niagara program head office and a local high school used for the Toronto program's monthly evening events) helped ease both respondent and parental concerns, in turn increasing the likelihood of participation.

Third, running the focus groups in a dedicated young carer program location with program staff on hand during each focus group (albeit, in separate rooms to preserve respondent confidentiality) provided young carers the opportunity to speak with support workers during or after the discussion should they have experienced any discomfort.

Fourth, each focus group was held on a dedicated 'young carer program night' which removed the need to schedule separate focus group events outside of the time young carers had already reserved for their weekly or monthly program attendance. This has been shown to be an effective strategy among international young carer researchers who note the benefits of a design that prevents an additional encroachment of young carers' very limited free time (Smyth, Blaxland & Cass, 2011). The only exclusion to this protocol occurred with the solo interview, which occurred at a restaurant chosen by the respondent for ease of access.

Fifth and last, a focus group design worked to minimize issues of power between the researcher/participant, a frequently cited issue when studying child and youth populations (Christensen, 2004; Davis, 1998; DeRoche & Lahman, 2008). By allowing youth to lead the discussion and build off of one another's commentary, while also interjecting my own experiences as a young adult carer to develop rapport with the group, I was able to reduce the uneven power relationship between myself as the interviewer and the youth as my interviewees. For a review of the full set of questions asked, refer to Appendix C.

After deciding on this research design, my next step involved contacting two of the three current Canadian young carer program staff (one in Toronto, one in the Niagara region) to discuss the project and coordinate joint efforts at recruitment. This entailed working with staff to arrange self-created electronic and print posters (Appendix B) to be sent out to the households of eligible program users. Young carers and their parents contacted me directly after that point and follow up communications were carried out with interested participants in order to provide relevant logistical information (related to the time and date of the focus groups) and to provide participants (and their parents) with electronic informed consent documents to review prior to the focus group. Participants aged 16 or older could provide their own consent while those aged 15 required parental consent to participate (see Appendix D for a copy of the consent form). Finally, ethics approval was sought and approved by the York University Office of Research Ethics.

Two focus groups were run during two young carer program sessions, one in Toronto (February 10, 2015, n=10) and the other in the Niagara region (March, 19, 2015, n=4) of Southern Ontario. While the majority of participants took part in one of the two focus groups (separated by program), one additional solo interview was completed in June 2015 with a young carer who had received program support in the past but was not currently attending programming. Given that the rest of the respondents possessed a familiarity with one another as current members of the same young carer program, which theoretically would ease their comfort with sharing their respective young carer experiences in a group format, the final 15th respondent was interviewed separately due to that corresponding lack of familiarity.

Finally, with the Toronto program known to have a younger participant user base contrasted with the Niagara group (which had a more diverse age range of users), the decision was also made to stratify the groups along age lines, a factor shown to be influential in terms of communication style and knowledge level (Charlesworth, & Rodwell, 1997). Efforts were thus made to keep each group relatively close in age range, by selecting older participants from the Niagara program (i.e., aged 17 to 18) and young(er) carers from the Toronto program (i.e., aged 15 to 16). This strategy accounts for the potential developmental and experiential differences between young carers beginning their high school careers and those nearing its completion and contemplating postsecondary plans.

Group interviews lasted roughly 90 minutes in duration (with the final solo interview lasting 60 minutes) and were recorded with the participants' consent and transcribed in full for subsequent analysis. Unlike the adult-based staff interviews, whose consent was secured verbally over the telephone, the consent process for youth participants was provided in person, with an electronic copy sent to the parents one week prior to the interview date in order to have them review and sign the consent (where necessary for youth under the age of sixteen). Food and beverages were also provided prior to the discussion commencing, an additional strategy to ease comfort and allow participants to mingle with one another and myself ahead of the interviews. Finally, participants were asked to complete a short accompanying survey once the interviews were complete (See Appendix E). The survey data represented a form of "concurrent" triangulation (i.e., using one or more data sources as a means to validate sample data) and probed a range of areas, including those related to the sociodemographic profile of participants (e.g. ethnicity, age, gender, household income, level and duration of caregiving), in addition to educational, employment and coping-based questions. The survey instrument was pretested amongst a convenience sample of public school educators in order to gage the appropriateness of wording and level of complexity amongst the targeted age-range. At the end of the interviews, participants were provided with a CAD $20.00 cash honorarium to thank them for their involvement in the project.

As Table 3.1 shows, the mean age of participants was 16 years, with a younger participant base in the first focus group (x=15 years) relative to the second (x=17 years) and the solo interview. Participants had been providing care for an average of 5.5 years, the level of which increased with age (indicating that young carers may very well continue to provide care into adulthood) and they provided an average of 23 hours of care per week. Although attempts were made to get an equal breakdown of male and female participants, only 20% (3/15) of the sample was male. While a slight majority of participants provided care primarily to a sibling (56%), a large minority cared for a parent (31%) while the remaining (13%) cared for multiple family members. Participants provided care for a variety of reasons, ranging from alcohol abuse to terminal cancer to autism and there was a high likelihood of co-morbidity with 31% of participants caring for relatives with more than one illness or disability. Lastly, while 44% of participants self-identified as Caucasian, the remaining 56% represented a range of ethno-racial profiles from Chinese to Arab to South Asian.

Table 3.1: Socio-demographic profile of focus group participants (N=15)

Focus Group 1 (N=10)

Age	Sex	Care receiver	Illness / Disability	Race / Ethnicity	Hours of care/week	No. of years caregiving
15	Female	Sibling	Autism, Mental Illness	Chinese	28	6
15	Female	Sibling	Epilepsy, Mental Illness	South Asian	40	4
15	Female	Parent	Terminal Cancer	Caucasian	35	6
15	Male	Sibling	Autism	Chinese	7.5	7
15	Female	Parent	Double amputee due to blood clots	Caucasian	21	3
16	Male	Sibling	Autism	Caucasian	1	3
16	Female	Sibling	Autism	Chinese	30	6
15	Female	Sibling	Asperger's syndrome.	Caucasian	7	4
15	Female	Parent, Sibling	Autism, Brain damage	Caucasian	50	10
15	Female	Sibling	Autism	Caucasian	7.5	4
Mean age (x)=15					**x=20.6**	**x=4.8**

Focus Group 2 (N=4)

Age	Sex	Care receiver	Illness / Disability	Race / Ethnicity	Hours of care/week	No. of years caregiving
17	Female	Parent	Double amputee due to diabetes	Arab	10	11
17	Female	Parent	Translation	Arab	7	8
17	Female	Parent, sibling, grandparent	Diabetes	Black	50	6
18	Male	Parent	Alcohol addiction, Mental illness	Caucasian	60	5
Mean age (x) = 17					**x=31.75**	**x=7.5**

Solo Interview (N=1)

Age	Sex	Care receiver	Illness/ Disability	Race / Ethnicity	Hours of care/week	No. of years caregiving
18	Female	Sibling	Autism	Caucasian	12	8

3.4.3 Limitations of Qualitative data sources

Despite this study representing one of only two first-hand accounts of youth-based caregiving by Canadian youth, some limitations exist. First, while added effort was made to recruit an even split of female and male young carers, the majority of respondents were female. This finding may be reflective of global evidence showing young girls are more likely to be drawn into caregiving than their male counterparts (Becker & Becker 2008; Cass et al., 2009; Eley, 2004; Frank & McLarnon, 2008; ONS, 2013; Robson, 2004; Roche & Tucker, 2003). It may also reflect research demonstrating that boys find it more difficult to get recognition as carers and subsequently become ‘invisible’ to pastoral care and other counseling services (Eley, 2004).

Second, while participants were recruited from two of the three existing young carer programs (one in Toronto and one in the Niagara region), those from the final Vancouver Island-based program were omitted from the sample. The primary reason for this exclusion involved the distance from the researcher’s home-base in the Greater Toronto Area and financial and time-based limitations with travelling to British Columbia. Online (skype-based) focus groups were considered for prospective BC-based participants but were ruled out for two key reasons. For one, the added difficulty in coordinating skype based focus groups with youth outside of a dedicated program setting has been noted by others using this method with child and youth samples. Nichols et al. (2011) highlight some of the difficulties experienced when employing skype-based focus groups in their study of children of patients with Frontotemporal dementia (FTD):

> Potential participants had difficulty agreeing on a date and time that did not conflict with their extracurricular activities or simply did not follow-up in the attempts to follow-up on scheduling. We ultimately distributed an email request to the parents of the potential participants asking for their assistance in convening the children. (Nichols et al., 2011, p. 23)

Additionally, my desire to provide the optimal environment for developing rapport and easing comfort by conducting the interviews in person, with opportunities to converse over food and drink beforehand, worked against using an online method. It is for these reasons that this sample only includes young carers affiliated with Southern Ontarian-based young carer programs.

Third, while interviewing young carers located through young carer programs provides a valuable account of youth formally identified as “carers” (by themselves, their parents and their social service providers), it does not necessarily account for the experiences of those hidden young carers not receiving assistance who, arguably, represent a qualitatively different cohort of young carers. Follow-up research should target those more marginalized young carers who are currently out of view from social service and healthcare professionals and likely have yet to identify themselves as caregivers.

Fourth, with a sample mean age of participants being 16 years, this study leaves out the experiences of those young(er) carers under the age of 15 years and those young adult carers (aged 18 to 24 years). Including both younger and older young carers in future samples will shed light onto how findings from this study shift or stabilize from childhood to adulthood and whether the noted benefits and/or penalties of early caregiving accrue overtime. When it comes to the impacts of caregiving on paid employment, as one example, an older sample of young adult carers aged 18 to 24 can more fruitfully highlight potential labour market experiences and interruptions into adulthood. It may be the case that many of the young carers in this sample have yet to begin looking for part-time paid employment, thereby limiting the findings for this particular penalty dimension.

A fifth and broader caveat to make is that this group represents a distinct category of youth that is providing unpaid reproductive labour in the context of familial illness, disability or substance use problems. This leads to findings that overestimate the experiences of youth providing some of the more time-intense, personal care or “activities of daily living” (ADL’s)[19] (e.g., bathing, dressing, feeding, toileting and administering medicine) relative to those youth providing more instrumental forms of reproductive labour (e.g., housekeeping, meal preparation, shopping and sibling care) in the context of familial fragility exacerbated by our current global capitalist economy.

---

[19] Duxbury & Higgins (2012) define Activities of daily living (ADLs) as the day-to-day basic support, or “personal care” which includes activities such as bathing, dressing, feeding, toileting and transferring from chair or bed. Instrumental care includes all those activities of daily living (IADLs) such as housekeeping, meal preparation, home maintenance, banking, shopping and transportation (p.20).

Sixth and last, there were some topics that arose within the group discussion that could have benefited from a one-to-one interview design. When probing the consequences of care, as an example, one participant noted her struggles with "anorexia, depression and anxiety disorder" but I did not feel it was the appropriate context to probe those experiences more fully in front of the group[20].

3.5 REFLECTIONS

The process of data collection and analysis answered as many questions as it raised new ones. By documenting roadblocks encountered along the way, I was able to understand how previously unanticipated difficulties inherent in studying this population posed potential for follow-up research.

One of the largest revelations involved the need for a whole-family approach to the study of youth-based caregiving. Interestingly, global young carer experts have highlighted the importance of a *Whole-Family Approach* with regard to the assessment of all individuals with an illness or disability, a model aimed at better identifying potential young carers at the first point of contact with a care or service provider (Social Exclusion Task Force, 2008). Existing research, however, has only explored youth-based caregiving from the perspective of either youth themselves, their parents, or service providers known to assist them. Thus, while my current design proved fruitful in gaining valuable first-hand information about the daily lives of young carers, the challenges to supporting them outside of their households and the national patterning of their care-work, there existed gaps in the data that would have benefitted from involvement of the whole family in the research design.

---

[20] I offered to connect this participant with local support services but was informed that such services had already been offered and were indeed being accessed.

First, I quickly became aware that survey questions developed for adult use were impractical when applied to youth. Asking youth about their total household income, a theoretically important variable impacting children's increased usefulness, produced a host of 'Don't Knows' that in hindsight was to be expected. Relying on national survey data to supplement these estimates is also risky given the well documented fact that income questions tend to produce comparatively higher non-response rates, greater measurement error via misreporting and higher response refusals in all surveys (Tourangeau & Yan, 2007, p. 860). Arguably, only participating parental figures who have developed trusting relationships with researchers in the area can provide this data.

Second, when comparing interview responses from the qualitative data and the short attendant survey, it became clear that utilizing a time-use diary to track the types and amount of care-work provided would have been beneficial. A mismatch between survey responses and group discussion accounts revealed a tendency for both memory recall issues and broader eligibility confusion, resulting in a misreporting of care-work provided in an average week whereby respondents tended to underestimate or overestimate time spent in these tasks. For example, if a respondent provided a weekly total of 7.5 hours of unpaid care on their survey but indicated in the focus group that part of their routine involved supervising their sibling for two hours each week night, it became clear that this time was not being factored into the total. Alternatively, another respondent's focus group revelation that his caring tasks ran "24 hours a day" mismatched his survey response of 60 hours of care provided per week. Now, this confusion could be attributed to difficulties with the mathematical computation of the total weekly figure but it could also be attributed in part to the broader confusion regarding what is considered normal exchanges of family life versus those pertaining to the delivery of care. This last point has been noted as an issue in relation to the surveying of adult caregivers (Walker, Pratt & Eddy, 1995). Without being able to pinpoint the exact source of error, it was clear that a more concise and on-going accounting of the care tasks provided in a given week, with additional instruction as to which duties count as care, would improve the reliability and validity of the quantitative survey data and the trustworthiness of the qualitative interview data. As a methodological note in favour of multimethod designs, I was only able to discover these inconsistencies due to the concurrent incorporation of the two methods within the same study. As reiterated by others using multimethod research, one of the promises of such designs lies with this very ability to tease out how such clashes between quantitative (in this case, survey) data and qualitative (in this case, interview) data can provide added insights into their respective strengths and limitations (Bryman, 2006).

While my research had some limitations, I must take a moment to reflect on its general strengths. First, the quantitative leg of my study opened up an array of issues and challenges with existing national datasets (and their survey instruments) that had yet to be explored in the Canadian literature while simultaneously providing the first known prevalence estimates of youth-based caregiving across Canada. It also provided supporting evidence for global studies using similar national data to explore youth-based caregiving while unearthing novel findings not reported by others in the field.

Second, my positionality as a previous young adult carer helped increase the soundness of my qualitative data by enabling a unique rapport to be developed with my subjects that I firmly believe emerged out of our shared caregiver standpoint and/or positionality. Interjecting my first-hand experiences with caregiving during the focus group discussion, as well as with the participant's parents (who may have been initially ambivalent about their child's involvement in the study), helped increase overall participation in the study but also put my subjects at ease in order to share their personal stories without fear of judgment or reprisal. The benefits of this shared positionality were evident by the subsequent ease of the interviews. As one example, my sole one-to-one interview lasted an extra 45 minutes after the interview wrapped due to the participant wanting to extend our conversation beyond the questions that prepared for the interview. Even after gently reminding the individual twice that our interview was over and that she could telephone her parent who was to come pick her up, her decision to stay signaled a moment of personal reflection for me; this interview was as much of an opportunity for her to have her voice heard as it was an opportunity for respite from her care-work at home. By the same token, this added rapport made it difficult for me to resist the urge to provide extra guidance and support to my participants from one carer to another – a factor that I had anticipated prior to data collection which facilitated my heightened sensitivity to the issue when in the field.

In the end, my personal experiences with unpaid familial caregiving provided for a more careful consideration of the needs of young carers and that in turn provided for more dependable data and results.

CHAPTER FOUR[21]

The Hidden Army of Young Carers in Canada: A Statistical Overview of caregiving among Canadian youth aged 15 to 24.

4.1 INTRODUCTION

When Saul Becker pointed to the existence of a 'hidden army' of young carers in the United Kingdom, he was referring to 2001 census figures revealing close to 175,000 youth under the age of 17 providing some level of unpaid care (Becker, 2007, p. 27). Despite this figure triggering a national spotlight on the phenomenon just over a decade ago, very little media or scholarly attention has been paid to these youth in North America and no comparable statistics have been compiled for Canada. The Canadian literature on caregiving, particularly that pertaining to care for older persons, has focused almost exclusively on the impacts of caregiving on adult women and families.

As it stands, only two sets of official country-level data have been analyzed in relation to the prevalence of young carers, with the most recent 2011 U.K. census indicating the presence of 432,250 young carers aged 5–25 in England and Wales (ADASS, 2014), and another 119,441 young carers aged 15–24 in Australia as of 2006 [22] (Cass et al., 2009, p. 31). Of the existing empirical research in Canada, only one study out of British Columbia had systematically explored the issue, with a survey of 483 high school youth indicating young carers represented 12.2% of

---

[21] This chapter is a re-worked and expanded version of the published article entitled: One Million and Counting: The Hidden Army of Young Carers in Canada (Stamatopoulos, 2015)

[22] These statistics refer to all youth providing any level of unpaid care.

that population (Charles, Marshall & Stainton, 2010). What is needed now, however, is information on the incidence and growth of young carers nationally as well as provincially – a point reiterated by a recent Action Canada Task Force on Young Carers (2013).

This research provides the first trend analysis of youth-based caregiving in Canada. In a first set of analyses, Canadian census data from 1996 to 2006 is used to: (1) track the national and provincial incidence and growth of youth-based caregiving, (2) highlight gender and age-related variation to the type of care (senior versus childcare) and, (3) explore the level of care provided. A second set of analyses makes use of data from the more detailed, yet less representative, 26th cycle of the General Social Survey (2012). Doing so nuances the census results in order to: (1) produce more recent prevalence estimates for the ten provinces; (2) highlight the socio-demographic characteristics of caregivers and their care receivers and, (3) assess the role of gender on decisions surrounding the choice of caregiver in addition to the level and types of care provided.

4.2 IDENTIFYING YOUNG CARERS IN CANADA

Identifying young carers is a difficult and sometimes impossible task. In most cases, existing data sources for which statistics on young carers are pulled reflect parental reporting of children's answers, which can underestimate youth-based care in many situations. Specifically, Becker (2007) notes that for U.K. census data on young carers, parental self-reporting of their children's care work fails to adequately identify or enumerate children in some caring situations, notably those who may be caring for parents who misuse alcohol or drugs or where there is enduring parental mental illness or HIV/AIDS. Nevertheless, country-level data can provide important minimum values on youth-based caregiving and have proven to be a powerful tool in promoting awareness and securing public policy supports for young carers outside of Canada.

4.2.1 The Canadian census

In Canada, an unpaid work module was included in the quinquennial 1996, 2001 and 2006 long-form census before being eliminated with the introduction of the 2011 National Household Survey. In fact, the Canadian census began probing measures of unpaid care earlier than both the British and Australian censuses, having theirs introduced in 2001 and 2006, respectively. When included, the module consisted of three questions relating to: (1) unpaid housework, yard work or home maintenance; (2) the looking after of one's own children, or the children of others without pay; and (3) any care or assistance provided to seniors without pay. For the purposes of this research, only those latter two questions related to unpaid care provided to individuals were included for analysis:

- ***Last week, how many hours did this person spend doing the following activities:*** (2) Looking after one or more of this person's own children, or the children of others, without pay? Some examples include: bathing or playing with young children, driving children to sports activities or helping them with homework, talking with teens about their problems, etc., and;
- ***Last week, how many hours did this person spend doing the following activities:*** (3) Providing unpaid care or assistance to one or more seniors? Some examples include: providing personal care to a senior family member, visiting seniors, talking with them on the telephone, helping them with shopping, banking or with taking medication, etcetera (Statistics Canada 2006b, p. 20).

Respondents were able to choose from one of five options that best reflected their level of care in the preceding week. For unpaid senior care, a smaller range of responses was provided (i.e. none, less than 5 hours, 5–9 hours, 10–19 hours and 20 hours or more) compared to those given for unpaid childcare (none, less than 5 hours, 5–14 hours, 15–29 hours, 30–59 hours and 60 hours or more).

An important note to mention involves the lack of census specification regarding *why* the care work was provided in addition to the over specification relating to *whom* the care was provided[23]. The Australian and U.K. census questions reflect not only the explicit qualifier that respondents provide care due to disability, long term illness or problems related to age but also offer carte blanche as to whom the care is provided. To be exact, the 2006 Australian census question, "In the last two weeks did the person spend time providing unpaid care, help or assistance to family members or others because of a disability, a long-term illness or problems related to age?" was asked of all persons aged 15 years or older and provided a yes or no response option (Cass et al., 2009, p. 23). The 2001 and 2011 U.K. census question, "Do you look after, or give any help or support to family members, friends, neighbours, or others because of: i) long-term illness or mental ill-health/disability? or, ii) problems related to old age?" was asked of all persons (irrespective of age) and was based on the respondents' "time spent in a typical week" which was captured by three response options: 1-19 hours, 20-49 hours a week and 50+ hours a week (ONS, 2011, p. 11).

Since the Canadian census fails to include such an explicit qualification as to why the care was provided, in addition to its focus on senior and child care, the figures eliminate some young carers (i.e. any children under the age of 15 as well as those aged 15 or older who provide care to *parents or other adults*) while overestimating others (i.e. those youth aged 15 or older providing added sibling care resulting from parental absence or incapacity). While this methodological variation reduces the ability to make more conceptually valid cross-national comparisons on the prevalence of young carers, it does not negate the census' validity with

---

[23] For more information on the limits of the census module on unpaid caregiving, refer to Chapter Three, section 3.3.2 (limitations).

respect to measures of unpaid care provided to children and seniors by Canadian youth between the ages of 15–24.

4.2.2 The General Social Survey: Cycle 26 on Caregiving and Care Receiving

One of the main justifications provided for the removal of the unpaid work module from more recent census questionnaires involves the General Social Survey (GSS), particularly the most recent 26th cycle of GSS dedicated to 'Caregiving and Care-Receiving'. This survey provides an expanded view of caregiving from the perspective of both the caregiver but also the primary care-receiver by collecting information on the types of help received and provided in addition to the range of coping mechanisms and general supports employed by caregivers. By further counting care provided to individuals of all ages (not merely children or seniors) and stipulating that the caregiving be provided in the context of aging and/or long-term illness or disability, the GSS enumerates a sample of respondents much more in line with those captured in Australian and U.K. national survey data.

For the purposes of this analysis, all those respondents aged 15 to 24 years who answered 'yes' to either of the following two parameter questions were included in the sample:

- ICG_Q110: During the past 12 months, have you helped or cared for someone who had a long-term health condition or a physical or mental disability?
- ICG_Q115: During the past 12 months, have you helped or cared for someone who had problems related to aging? (Statistics Canada 2012b).

Respondents answering yes to one or both of these questions were then filtered into the "caregiver" category and provided specific interview questions based on a range of foci specific to their caregiver status. Some of these explored in this chapter include the hours of care provided per week, the types of care tasks performed and the main reasons for the provision of their care and support. Unlike the census though, the GSS's failure to enumerate Northern Canada renders it incapable of providing national estimates. While these and other inconsistencies between the two datasets (see Chapter Three) prevent us from making strict comparisons between the two sets of statistics, they nevertheless complement one another and reveal valuable information about these potentially different groups of young carers.

4.3 ANALYSIS I

The first set of analyses were conducted using 1996 and 2006 Census Public Use Microdata Files (PUMF) on individuals, containing data based on a 2.45% sample of the population in 1996 (N=723,486) and 2.7% in 2006 (N= 844,746) in 2006 (Statistics Canada, 1996, 2006a). In order to avoid conflating the sample with potential young parents, who invariably provide significant unpaid childcare per week, analysis of that particular variable was limited to non-parents. This resulted in two different samples produced for the analysis of child care: one for married or common law youth with no children present in their household and the other for all those single, non-lone parent youths aged 15 to 24 (irrespective of the presence of children in their household). Analyses of the final unpaid senior care variable were run for all youth aged 15 to 24. Finally, the basic weighting factor (i.e., 'WEIGHT') for the person level was used for all analyses and aimed to correct for under- or over-representation of persons occurring in the smaller, long-form census file. As one example, one-person households and young males tend to be under-represented in the long-form census file and thus have their probability weights adjusted upwards in the creation of survey weights, while married people, who tend to be over-represented, have their probability weights adjusted downwards (Roberts, 2012). In the three 1996, 2001, and 2006 long form censuses, the weight adjustment process was such that a single survey weight variable ('WEIGHT') was provided for all person-level analyses. It is this weighting factor that is used to obtain the population estimates contained in this first analysis.

4.3.1 Incidence and growth

In 2006, over 1.18 million youth between the ages of 15 and 24 (28.2%) provided some level of unpaid care in Canada, representing a 13.5% increase from 1996 (Table 4.1). Significant provincial variation existed among the proportion and level of overtime change, with a staggering 46% of youth in Northern Canada (i.e. Yukon, Northwest Territories and Nunavut) providing some level of unpaid care in 2006 compared to a low of 25.8% for Quebec youth.

Table 4.1. Proportion, number and percentage change of young carers aged 15 to 24 years in Canada, between 1996 and 2006.

Province	Proportion providing unpaid care		Number of young unpaid carers		*Percentage change between 1996 and 2006*
	1996 (%)	2006 (%)	1996	2006	
Canada	**27.2%**	**28.2%**	**1,040,904**	**1,180,924**	**13.5%**
Nfld & Labrador	29.3%	26.4%	25,812	16,983	-34.2%
Prince Edward Island	31.5%	32.4%	5,868	6,031	2.8%
Nova Scotia	28.3%	26.6%	34,632	31,409	-9.3%
New Brunswick	28.5%	26.5%	29,808	24,343	-18.3%
Quebec	24.8%	25.8%	231,984	241,873	4.3%
Ontario	27.2%	29.7%	378,864	482,929	27.5%
Manitoba	32.5%	33.1%	49,932	52,866	5.9%
Saskatchewan	35.0%	32.5%	48,780	45,727	-6.3%
Alberta	28.1%	26.6%	103,068	129,004	25.2%
British Columbia	25.9%	26.9%	125,352	142,840	13.9%
Northern Canada	47.6%	46.0%	6,804	6,919	1.7%

Furthermore, Newfoundland and Labrador experienced a sizeable 34.2% decrease in the number of youths providing unpaid care between 1996 and 2006 while Ontario experienced the largest increase with a 27.5% jump (Table 4.1). Potential explanations for the provincial variation observed will be provided in section 4.4.1 to additionally account for similar variation in the GSS data.

4.3.2 Characteristics of young carers and the type of caregiving provided

Delineation vis-à-vis the type of care provided (senior versus child) is a feature exclusive to the Canadian census, permitting added clarification unavailable from other country-level census data. As shown in Table 4.2, the majority of all unpaid care in 2006 was provided to children (60%, 707,337) compared to seniors (40%, 473,570). For childcare, the majority of all care was provided by non-married-common law youth (i.e., those youth living with parents, other relatives or on their own (671,599) compared to those married or common law youth living together on their own (35,738).

Expanding on this and pursuant to the literature in the adult-based care literature, it is well documented that gender is a long-standing determining factor in the provision of unpaid care among adults. The effects of gender in the global young carer literature, however, are mixed. In the U.S, a near even gender split was found for young carers aged 8–18 in a random sample of 2,000 U.S. households conducted in September 2003 (National Alliance for Caregiving/United Hospital Fund, 2005, p. 3). Australian census data reveals an age-progressive pattern whereby similar proportions of young men and women aged 15–19 report caregiving responsibilities, with a growing feminization of care as youth age (Cass et al., 2009, p. viii). Across England and Wales, 2011 census data show that girls aged 5–17 provide more unpaid care than boys across all regions (ONS, 2013).

For the Canadian census data, and similar to the U.K. results, the majority of all young carers were female (54%) but the proportions varied by both the type of care provided and by the youth’s census family type categorization (e.g., married/common-law, non-married/common-law). The most drastic gender disparity was observed for child care provided by married or common-law youth aged 15 to 24, whereby 74% of all care was provided by females (Table 4.2). Compared to the remaining care totals, which fluctuate roughly around 54%, this particular relationship status suggests that more ardent gender-roles attached to husband/wife seemingly lag behind those newer roles afforded to single women and girls such as student and paid worker.

Results also reveal age-based differentials to youth-based caregiving, with the majority of youth-based caregiving provided by 15 to 17 year olds (39%) and 20 to 24 year olds (40%), with age and marital status further impacting the type of care provided. Specifically, the provision of childcare reveals interesting results based on marital status, with young(er) carers (aged 15‒17) providing the greatest proportion of child care among those non-married/common-law youth (45%, 305,796) switching to young adult carers aged 20 to 24 (86%, 30,734) who provide the lion’s share among married/common-law youth. Young carers aged 18–19 serve as a unique sandwich generation of young carers, providing only 21% (244,978) of all youth-based care, with this breaking down to 20% for senior care and 22% for child care among non-married/common-law youth and an even lower 10% for child care among married/common-law youth. This pattern potentially reflects the transition period from high school to paid employment and/or postsecondary education (Table 4.2).

Table 4.2. Characteristics of young carers aged 15 to 24 by type of care provided, 2006 (CANADA).

	TYPE OF CARE PROVIDED			
	Child Care (60%)		Senior Care (40%)	Total Care (100%)
	married / common law (n=35,738)	non-married/ common law (n=671,599)±	All youth (n=473,570)	
Sex of caregiver				
Female	74%	54%	53%	54%
Male	26%	46%	47%	46%
Age				
15 to 17	4%	45%	33%	39%
18 to 19	10%	22%	20%	21%
20 to 24	86%	33%	47%	40%
Visible Minority Status				
Not a visible minoriity	88%	77%	79%	77.5%
South asian	5%	6%	7%	6.7%
Chinese	2%	4%	6%	4.3%
Black	1%	5%	3%	4.0%
Other †	4%	8%	5%	7.5%
Immigrant Status				
Immigrants	15%	17%	14%	15.7%
Non-immigrants	84%	82%	85%	83.3%
non-permanent residents	*2%*	*1%*	1%	1.0%
Household Income				
Under $50,000	49%	31%	31%	31%
$50,000-$99,999	38%	38%	35%	37%
$100,000 or more	14%	31%	34%	32%
Census Family Living Arrangement				
Married male	7%		0.8%	0.5%
Married female	24%		2.5%	1.7%
Common law male	19%		1.7%	1.3%
Common law female	50%		4.3%	3.2%
Lone parent male	--	--	0.3%	0.1%
Lone parent female	--	--	1.7%	0.7%
Child of married/common law couple		71%	65.0%	66.5%
Child in lone-parent family		20%	16.1%	17.8%
Living with other relatives		3%	1.8%	2.4%
Living alone		2%	2.6%	2.4%
Living alone with non-relatives		4%	3.0%	3.5%

Dataset: Census of population, individuals file, 2006.

Note. Figures may not add up to 100 in some places due to rounding.

† Other includes: Filipino, Latin American, Southeast Asian, Arab, West Asian, Korean, Japanese, visible minority n.i.e (written in responses), and multiple visible minority.

N=1,180,907 (Weighted sample)

With literature strongly suggesting that young carers tend to be primarily located in low−income families and in families of immigrant and/or culturally and linguistically diverse backgrounds (Becker, 1995; Cass et al, 2009; Charles, Stainton & Marshall, 2010; Smyth, Blaxland & Cass, 2011), visible minority, immigrant status and total household income were variables of interest included in this analysis. Despite underreporting found to be particularly common among some minority youth, because caregiving is simply accepted as part of one's normal familial obligation (EDAC, 2003; Hill, Smyth, Thomson & Cass, 2009; Misic, 1996), the clear majority of young carers in 2006 were non-immigrants (83%) and not of a visible minority (77.5%). With that said, a point for follow-up research could involve more in-depth assessments of potential underreporting among minority youth and adults who are often reporting on behalf of their children.

As for income, the aggregated results showed a rather close split among the three income groupings, with those of the lowest income having the lowest proportion of caregivers (31%) compared to those in the middle income category (37%) and the highest income category (32%) [Table 4.2]. While at the outset this may appear to deny the role of income or class in care decisions, it may actually provide proof of the increasing necessity of both parents to enter the paid labour market as discussed in the first two chapters, which in turn naturally elevates total household income while simultaneously leaving gaps in reproductive labour that were previously provided by stay-at-home mothers. The only instance where lower total household income correlated with increased caregiving were for those married/common law youth providing child care, whose proportion of caregiving decreased with each increasing income bracket from 49% to 38% to 14% (Table 4.2). When factoring in the youth's census family living arrangement grouping, it becomes clear that this pattern may actually reflect the added gender constraints linked to this particular marital status, particularly the dual tendency for married and common-law females to scale back on paid work in order to provide such family care and/or to accept more casual, part-time forms of paid work as a response. It would make sense that these households have lower total household incomes since the female spouse/partner is providing the lion's share of such reproductive care. On the other side of the marital status coin, this may also explain the more egalitarian division of child and senior care among non-married/common-law females who do not face such added pressure to conform to gendered conventions surrounding the 'appropriate' or 'natural' role of wives and partners in the unpaid (reproductive) care economy.

Finally, the inclusion of the 'census family living arrangement' variable affords the opportunity to assess whether Australian census data, showing that lone parenthood increases youth's proportion in unpaid caregiving (Cass et al., 2009), holds true for Canadian youth. Results indicate that despite the majority of young carers belonging to intact families, that is, children of married or common-law couples (66.5%, 783,361), the second largest grouping belonged to youth from lone-parent families (17.8%, 209,760). Additionally, children of lone-parent families were more likely to be providing care to other children (20%, 134,290) which makes sense in the context of added sibling care that is often crucial to sustaining lone-parent families where the sole parent is in the paid labour market and the purchasing of supplementary child care is not an option.

4.3.3 Level of care by sex, age and census family status

The majority of youth (68%, 798,787) provided less than five hours of combined senior and/or child care per week in 2006. However close to 67,000 of youth (5.6%) provided upwards of 30 hours of child care (45,355) or 20 hours of senior care (20,792) [see Figure 4.1]. The level of care also varied depending on the type of care provided, with 77% of all young carers providing less than five hours of weekly care to seniors compared to a smaller 62% (for non-married/common-law youth) and 55% (for married/common-law youth) providing that same level to children, indicating a greater level of care provided to children and especially by married and common-law youth.

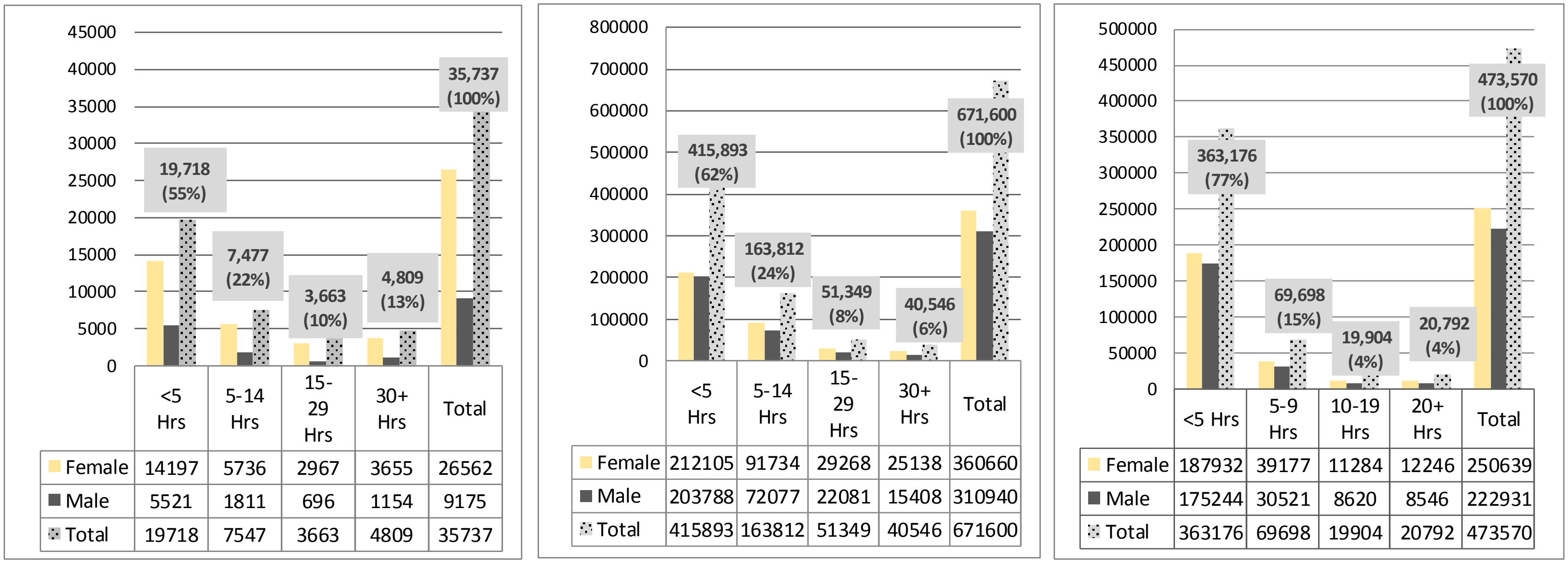
Finally, gender interacted with the type and level of care provided, with females more likely to contribute a greater level of care not only to both children and seniors but to also have their proportion of care rise incrementally with each care level. As Figure 4.1c shows, female young carers accounted for 53% (250,639) of all senior care but they accounted for only 52% (187,932) of those providing less than five hours of unpaid care per week, rising to 56% (39,177) of those providing 5–9 hours, to 57% (11,284) of those providing 10–19 hours, and 59% (12,246) of those providing 20 or more hours. This gendered pattern was most pronounced for child care, with non-married/common-law females accounting for 54% (360,660) of all childcare but only 51% (212,105) of those providing less than five hours of unpaid care per week, rising to 56% (91,734) of those providing 5–14 hours, 57% (29,268) of those providing 15–29 hours, and 62% (25,138) of those providing 30 or more hours (Figure 4.1b). A superlative gender effect was observed for married/common-law female youth providing child care. Such females saw their proportion of care rise from 72% (14,197) at the lowest care level to 76% (5,736) of those providing 5–14 hours to 81% (2,967) of those providing 15–29 hours before dipping to a still above average 76% (3,655) of those providing 30 or more hours (Figure 4.1a).

Circling back to the Australian census data finding of an age-progressive feminization of youth-based caregiving, the Canadian data revealed corroborating data that was dependent on the type of care provided and census family living arrangement. For senior care, a near perfect pattern of was observed, whereby females witnessed their proportion of care rise with age and it did so most appreciably at the highest care levels. As shown in Table 4.2c, female youth aged 15 to 17 account for 49% of all those providing 20 or more hours of care, rising to 59% for 18 to 19 year olds and topping out at 63% for 20 to 24 year olds. Male youths providing senior care saw their proportion of care decrease with age and care level, with 15 to 17 year olds holding a temporary majority for the highest care level (51%) before dropping to 41% for 18 to 19 year olds and 37% for 20 to 24 year olds (Figure 4.2c).

A less clear cut and consistent feminization of care occurs for child care. For non-married/common-law youth (Figure 4.2b), a near perfect pattern held but only for the highest care level. Here, non-married/common-law female youth aged 15–17 accounted for 57% of those providing 30 or more hours of childcare per week, rising to 66% for those aged 18–19 before slightly dipping to 65% among those aged 20–24. For married and common-law youth, the opposite pattern occurred. Although imperfect, female youth experience a decreasing level of childcare with age while the opposite pattern holds for male youth (Figure 4.2a). Despite married and common-law male youth taking on a greater share and level of unpaid child care with age, married and common-law females still carry the vast majority of all child care and across all care levels with the most drastic differentials at the highest care levels.

The general tendency for female young carers to be more heavily concentrated in childcare (and to provide greater levels of care to children) may be further evidence of early sex socialization, with girls more likely to feel the push/pull into a parenting role when the care is located within their households (for those non-married youth). Even when child care is located outside of the household, as is the case with youths in the ‘married or common-law’ census living arrangement, their status as wife/partner arguably adds a different and stronger set of gendered pressures that explains their substantially higher involvement and level of care provided.

Figure 4.1. Number of young carers aged 15 to 24 providing unpaid weekly *child care* (*a,b)* and *senior* care (c) by level of care and sex, 2006 (Canada).



(a) Married/Common-law youth

	<5 Hrs	5-14 Hrs	15-29 Hrs	30+ Hrs	Total
Female	14197	5736	2967	3655	26562
Male	5521	1811	696	1154	9175
Total	19718	7547	3663	4809	35737

(b) Non-married/common-law youth

	<5 Hrs	5-14 Hrs	15-29 Hrs	30+ Hrs	Total
Female	212105	91734	29268	25138	360660
Male	203788	72077	22081	15408	310940
Total	415893	163812	51349	40546	671600

(c) All youth aged 15 to 24

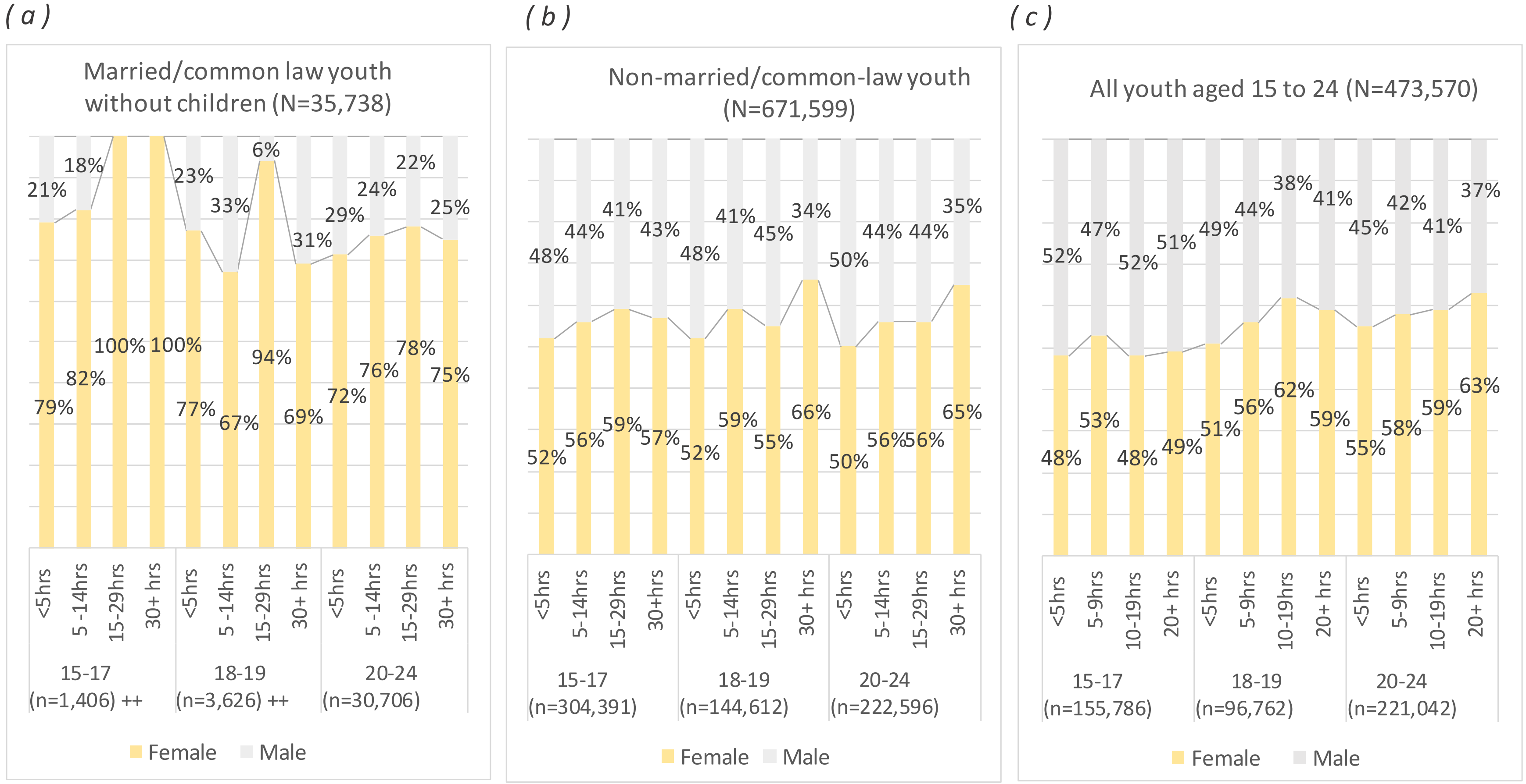
	<5 Hrs	5-9 Hrs	10-19 Hrs	20+ Hrs	Total
Female	187932	39177	11284	12246	250639
Male	175244	30521	8620	8546	222931
Total	363176	69698	19904	20792	473570

Dataset: Census of population, individuals file, 2006.

Note 1: Some totals might not add up to 100 due to rounding.

**N= 1,180,907 (Weighted sample)

Figure 4.2. Proportion of all young carers providing unpaid childcare (a,b) and unpaid senior care (c) in Canada, by age, sex and level of weekly care, 2006 (Canada).



Source: Census of population, individuals file, 2006.
Note: ++ Use with great caution
N= 1,180,907 (Weighted sample)

Indeed, the only instance where males outnumber females in the higher care levels (i.e., 5 or more hours) is with senior care (Figure 4.2c). This may reflect the greater acceptance with sending younger males outside of the household (compared to younger females) since the majority of senior care takes place in the private household of the older person(s). The dissipation of that male majority caring role past the age of 17, however, lends additional credence to the progressive impact of sex-based socialization into the historical domination of adult women in both paid and unpaid caregiving roles (Armstrong, 2003; Armstrong & Armstrong, 2005; Milan et al., 2011). Corroborating evidence for this can be found in both British and American research. One study of 120 young carers in England and Northern Ireland found that 80% of young carers taking the lead caring role within their households were female (Roche & Tucker, 2003, p. 449). In the United States, the sole child and youth-based caregiving survey, mailed to a random sample of 2,000 households in 2003, found that girls were more likely to provide care for siblings compared to boys (National Alliance for Caregiving/United Hospital Fund, 2005, p. 6). These findings echo others who argue that greater expectations are placed on girls to provide caring tasks and that females undertake more of the caring even if there are young males in the household (Becker & Becker, 2008; Eley, 2004).

4.4 ANALYSIS II

The second set of analyses were conducted with the 2012 General Social Survey (cycle 26) PUMF dedicated to "Caregiving and Care Receiving". This cycle interviewed individuals aged 15 years and over in Canada's ten provinces and was conducted from March 2012 to January 2013. Due to the potential difficulties in reaching care receivers, a special rejective sampling technique was used in order to include more respondents from this hard-to-reach population (Statistics Canada, 2012b). Similar to the census analysis, weighting adjustments were required in order to account for the nonresponse and sampling bias in the resulting GSS microdata file. For this cycle of the GSS, weight adjustments corrected biases pertaining to the province, care giving/receiving status, stratum, sex, and age of the respondent (Statistics Canada, 2012b). As an example, nonresponse was shown to be higher among males and younger persons, with 1.9% of persons in the responding PUMF being male and between the ages of 15 to 19 compared to the overall population where this figure was roughly 3.9% (Statistics Canada, 2012b). The resulting WGHT_PER factor (i.e., the basic weighting factor for analysis at the person level) was thus required to correct such imbalances and calculate estimates of the larger non-institutionalized population of persons aged 15 or over living in the ten provinces.

4.4.1 Incidence and Provincial Variation: 2012

Notwithstanding the GSS missing all those potential young carers in Northern Canada, over 1.25 million youth aged 15 to 24 provided some level of unpaid caregiving due to aging or long-term illness or disability in 2012, rendering them the third largest carer cohort (Table 4.3).

Table 4.3. Proportion of unpaid caregivers by age (groupings of 10), 2012 (Canada).

Age Group	**15 to 24**	**25 to 34**	**35 to 44**	**45 to 54**	**55 to 64**	**65 to 74**	**75 years +**	**Total**
Number	**1,250,536**	1,157,651	1,143,473	1,945,545	1,620,403	682,641	283,814	8,084,063
Percent	**15.5%**	14.3%	14.1%	24.1%	20.0%	8.4%	3.5%	100.0%

Source: Statistics Canada, General Social Survey, 2012.

Within the young carer cohort, and similar to the census results, the majority of young carers were aged 20 to 24 (53%, 666,368) followed by those aged 15 to 17 (28%, 354,791) and those aged 18 to 20 (18% 229,377). Despite enumerating different populations (with the exception of senior care), a relatively similar proportion of youth provided caregiving at the national level in 2012 (27.4%) compared to 2006 (28.4%) [Table 4.4].

In the absence of Northern Canada from the sample, it was Saskatchewan (38%), Alberta (31%), Manitoba (30.7%) and Ontario (30%) which had the highest proportions of young carers (Table 4.4). Similar to 2006, Quebec continued to have the lowest proportion of carers across Canada with 20.3%. The presence of consistently disparate provincial patterning to youth-based caregiving raises additional questions. In the absence of a more thorough investigation of each individual provincial landscape, the case of Quebec and Northern Canada can be used for illustrative purposes.

Table 4.4. Proportion and number of young carers aged 15 to 24 providing some level of unpaid care to family, friends or neighbours for a long-term illness, disability or reasons related to aging, 2012 (Canada).

Province	Proportion providing unpaid care	
	Number	%
CANADA	**1,250,536**	**27.4%**
Newfoundland & Labrador	12,549	21.0%
Prince Edward Island	5,007	24.5%
Nova Scotia	32,363	26.8%
New Brunswick	29,527	26.8%
Quebec	202,420	20.3%
Ontario	542,518	30.0%
Manitoba	55,186	30.7%
Saskatchewan	55,806	38.0%
Alberta	161,582	31.0%
British Columbia	153,576	25.4%

Source: Statistics Canada, General Social Survey, 2012.

Quebec's consistently lower rates are likely attributable to their unique familial policies that reflect the more Nordic-like model of governance that differs considerably from the rest of Canada (Beaujot, Du & Ravanera, 2013). Here, a variety of social policies work against greater numbers of people, irrespective of age, from taking on greater levels of unpaid care. First, the provision of $7.00 a day universal child-care since 1997, in addition to generous paternal and maternal parental leave since 2006, has enabled Quebec to avoid particularly low fertility rates while improving child welfare and women's employment opportunities (Stalker & Ornstein, 2013) as well as overall life satisfaction (Barrington-Leigh, 2013). Second, Quebec has taken the lead in addressing the growing healthcare needs for an aging population by reforming provincial policy to integrate hospital-based, nursing home, homecare and social services in 95 catchment areas. The resulting implementation of family medicine groups, network clinics, and various localized initiatives have succeeded at better integrating care for older persons and persons with chronic diseases (Vedel, Moette, Beland & Monette, 2011). Undoubtedly these policies play a decisive role in Quebec's consistently lower rates of youth-based caregiving (as evidenced in this analysis) but also the age-aggregated data showing that Quebec is the only province with caregiving rates that rest below the national average (Sinha, 2013).

On the other side of the coin, the alarmingly high rates of young carers found to exist in Northern Canada (census analysis) reflects the persistent lack of supportive policies to assist the majority Aboriginal population in the area (Simeone, 2008). Just as Quebec's more Nordic-style mode of governance works to reduce the level of unpaid caregiving required by youth, the demographic, economic and social conditions of Northern Canada's Aboriginal peoples operate to do just the opposite. The weakening of families resulting from the joint social and material consequences of Canada's century-long policy of forcible assimilation have led to diminished opportunities for Aboriginal populations to live well and thrive on their own terms. The impact on families is direct and unequivocal. Research reveals that the high incidence of a wide range of social problems in the North (e.g., higher unemployment, residential overcrowding, alcohol abuse, family violence and sexual abuse) link up to the higher than average number of children placed in out-of-home foster care, in addition to the increased reliance on older persons to help achieve familial stability (Farris-Manning & Zandstra, 2003; Milan & Hamm, 2003). Indeed, the rise of 'custodial grandparenting' or 'skip generation families' (i.e., grandparents living with their grandchildren in households where no parent is present) have been shown to result primarily from (parental) incarceration rates, chemical dependency and child welfare placements that occur in greater proportions among the Aboriginal population (Fuller-Thompson, 2005).

The role of Aboriginal children and youth in providing such substitute parenting (for their siblings and/or frail or sick grandparents) has been far less researched but certainly worth further consideration given the findings from the census analysis.

4.4.2 Characteristics of young carers

Added detail afforded by the GSS, related to the characteristics of both the care receiver and the caregiver, represents a methodological strength unavailable from other official comparable country level data[24]. The U.K. census, for example, only asks the broad question of whether the care was provided (not to whom) and the Australian data (i.e., Survey of Disability Ageing and Carers: SDAC) probes the relationship of the carer to the first recipient of care but only for co−resident carers. The Canadian GSS question probing the relationship between the care provider and primary care-receiver, irrespective of co-residency, provides a more comprehensive representation of the unpaid caregiving landscape.

Table 4.5 provides information about young carers that both parallels the census results while offering new and previously unavailable information. Similar to the 2006 Canadian census data, a majority of youth-based caregiving was provided by a single, never married (93.5%) and female (53%) majority. Young adult carers aged 20 to 24 (53%) comprise the largest carer cohort followed by younger carers aged 15 to 17 (29%). Young carers were also more likely to be located in intact families (65%) followed by lone-parent families (17%).

---

[24] The UK census and three nationally−representative Australian datasets—the Australian Bureau of Statistics (ABS) Census of Population and Housing 2006, the ABS Survey of Disability Ageing and Carers (SDAC) 2003 and Wave 5 of the Household Income and Labour Dynamics in Australia (HILDA) survey (Cass et al., 2009).

New information courtesy of the GSS includes the finding that the majority of all youth-based caregiving is provided in the context of long-term illness or disability (66%) and is provided by youth living in close proximity to their care receiver (i.e. in the same household or less than 10 minutes by car). Contrasted with the census which measures hours of weekly care at the ordinal level, the GSS measures this variable continuously (ratio level) with youth able to provide an exact number from 0-100. With this added detail we learn that young carers provide an average of 6.53 hours per week of unpaid caregiving, with a standard deviation of 11.13 indicating the data are spread out over a large range of values. The majority of Canadian youth (minus Northern Canada) provided under five hours of care per week in 2012, representing 63% of all youth aged 15 to 24 (Table 4.5). Notwithstanding this majority, just over 185,000 (15%) provided 15 or more hours of unpaid care per week, a figure exceeding the combined 121,159 youth shown in the census to provide either 15 hours or more of child care and 20 hours or more of senior care per week. This may reflect an overtime increase in the level of care provided (i.e., between 2006 and 2012) but it may also reflect the GSS's enumeration of youth providing care in the context of more serious illness and disability that requires added assistance than the more generalized sibling care enumerated by the more targeted census question.

Table 4.5 also reveals that the majority of youth-based caregiving was provided within large urban centers (83%) compared to rural and small population areas and it was by provided by youth citing "school" as their main activity (66%) or "working at a paid job or business" (26%).

Table 4.5 Characteristics of young carers (aged 15 to 24 years) and their primary care receiver, 2012 (CANADA)

YOUNG CARER			YOUNG CARER'S PRIMARY CARE RECEIVER		
Continous Variable	**Mean**	**Standard Deviation**	*Categorical Variables*		
Hours of care per week (0-100)	6.53	11.13	**Main health condition/problem for which care receiver received help**		
Categorical Variables			Arthritis (e.g., rheumatoid arthritis, osteoarthritis,lupus)	3.9	48,539
Category of care	**%**	**Number**	Chronic lung conditions (e.g., asthma, bronchitis, emphysema)	1.6	19,456
Long-term health condition or physical or mental disability	66	828,554	Cardiovascular disease (including angina, heart attack, stroke)	8.3	103,400
Problems related to aging	34	421,982	Diabetes	2.8	35,049
Sex			Back problems	4	50,310
Male	47	582,302	Cancer	8.9	110,829
Female	53	668,234	Injury resulting from an accident	4.6	57,967
Age grouping			Aging / old age / frailty (including Alzheimer's disease or dementia)	32.9	410,546
15 to 17	28	354,791	Mental illness (e.g., depression, bipolar disorder, mania or	8	99,644
18 to 19	18	229,377	All other neurological diseases (e.g., Parkinson's disease)	6.4	79,541
20 to 24	53	666,368	Developmental disability or disorder	3	37,712
Respondents Family Type			Joints problems	2.1	25,638
Couple only	3.5	42,466	Eye problems	1.9	23,593
Intact family	65	817,522	Mobility problems	1.2	15,527
Step-family	10	128,162	Addictions (drugs, alcohol)	0.6	7,832
Lone parent family	17	215,308	Physical disabilities	0.9	10,965
No spouse or children in household	4	47,078	All other	6	69,824
Distance			**Residence type of care receiver**		
In the same household or building	34	433,092	In a private household	89	1,077,407
Less than 10 minutes by car	29	359,031	In supportive housing	5	62,360
10 minutes to 30 minutes by car	21	267,896	In an institution or care facility (such as hospital or nursing home)	6	77,895
30 minutes or more by car	13	163,424	**Relationship between care receiver and the respondent**		
Population centres indicator			Father of respondent	10	121,476
Large urban population center	83	1,043,453	Mother of respondent	14	179,271
Rural areas and small population centres	17	209,872	Brother of respondent	2.3	28,671
Main activity of young carer			Sister of respondent	2.6	31,980
Going to school	66	824,813	Grandfather of respondent	10	128,626
Working at a paid job or business	26	324,430	Grandmother of respondent	36.5	456,061
Looking for paid work	4	53,101	Uncle of respondent	1.5	18,671
Other†	4	50,982	Aunt of respondent	2.3	29,219
Marital Status			Close friend of respondent	7.6	95,314
Married/common law	6	76,298	Neighbour of respondent	3.4	42,501
Widowed, separated, divorced	0.5	4,740	Co-worker	0.6	7,013
Single, never married	93.5	1,167,211	Other±	7	84,498
Total Household Income			**Types of assistance offered to care-receiver**		
Under $50,000	20.9	150,749	Transportation	62	777,584
$50,000-$99,999	30.6	221,198	Meal preparation, cleaning, laundry	67	835,383
$100,000 or more	48.5	350,406	House maintenance or outdoor work	62	771,014
Hours of care per week			Personal care (e.g., bathing, dressing)	17	212,852
Under 5 hours	63	790,388	Medical procedures or treatments	21	257,867
5 to 14 hours	22	277,908	Scheduling/coordinating care-related tasks	13	167,045
15 or more hours	15	185,029	Banking, bill paying or managing finances	8	100,875

Source: Statistics Canada, General Social Survey, 2012.

† Includes caring for children, household work, parental leave, long-term illness, providing care to family or friends.

± Includes spouse, ex-spouse, daughter, son, cousin, father/mother-in-law, neice/nephew, grandson or granddaughter of the respondent.

Note 1. Refers to help/care given to friends or family members because of a long-term health condition or a physical or mental disability or problems related to aging.

Note 2. Totals may not add up to 100 due to rounding.

Similar to the census, but with a more definitive and consistent positive relationship, the proportion of youth providing care increases with each increasing income level, from just shy of 21% for those in the lowest income grouping (under $50,000) to almost 49% for those in the highest income grouping ($100,000/or more)[25].

4.4.3 Characteristics of primary care receivers

Looking to the right half of Table 4.5, we see that youth provide unpaid care and support to persons living in private households (89%) who require assistance with a variety of tasks, the top three of being transportation, meal preparation (including cleaning and laundry) and household maintenance (including outdoor work). Although a variety of conditions facilitate care and support, the clear majority of persons receive care resulting from problems related to aging (32.9%) or cancer (8.9%). These findings reiterate the impacts of the rising silver tsunami amidst an increasing transfer of health and human services from the public to the private sector. As will be elaborated upon in Chapter Six, an increasing burden of care has been placed on families due to the lack of public and non-profit, community sector programs available to support them. This is the result of neoliberal-inspired health and social service restructuring aimed at avoiding the high costs of public long-term care.

A look at the top ten care relationships (representing 93% of all such caregiving dyads) confirms the impact of the graying of Canada upon youth. Almost half of all 15 to 24 year olds provide unpaid caregiving to a grandparent (46.5%), particularly a grandmother (36.5%) followed by a parent at a distant second (24%). As a methodological note, grandparents are the primary care receiver listed for 584,687 young carers yet only 421,982 youth cite providing care due to reasons

---

[25] Consistent with the broader underreporting of income questions on surveys (Tourangeau & Yan, 2007), this particular variable had a high (42%) nonresponse rate.

related to “aging”. While it may be the case that the just over 160,000 grandparents are receiving care for long-standing pre-existing illnesses, it may also be the case that some youth erroneously cited the provision of care for a ‘long-term illness or disability’ (ICG_Q110) that was likely the result of aging (ICG_Q115), especially in the case of many degenerative hearing, mobility, and vision-related conditions. If interviewers were not aware of this potential issue and failed to probe whether the long-term illness or disability was linked to aging during the preliminary caregiver identification questions (ICG_Q110 & ICG_Q115), then it may help explain some of this disparity. Of course, even if interviewers did take the extra step to clarify the main reason for care provision among youth, it also stands to reason whether youth would possess the requisite knowledge to make such associative links if probed.

An important yet largely overlooked area in the young carer literatures is unpaid care provided to *non-relatives*, with existing studies narrowing their focus to familial care, particularly co-resident familial care provided in the context of illness and/or disability. The results presented in both Tables 4.5 and 4.6 thus shed important and never before reported data on the provision of nonrelative care by young carers. Over 11% (144,828) of Canadian youth aged 15 to 25 provided unpaid care and support to non-relatives in 2012 (Table 4.5). Of particular interest is all of that unpaid care provided by youth to friends. Indeed, unpaid care provided to friends (7.6%) overtook the combined care provided to brothers *and* sisters (4.9%) and stood as the fifth largest caregiving dyad among Canadian youth aged 15 to 24. Second, the top cited reason for providing such care and support illustrates important differences, with the majority of care provided to close friends done so in the context of mental illness (36.5%), despite it failing to make the top three reasons cited for all remaining relative and non-relative care (Table 4.6). In the absence of qualitative data probing children and youths’ experiences with nonrelative care, both within this study and beyond, this finding raises additional questions. What factors promote this added reliance on youth to act as informal mental health support persons for other youth? Could this finding be tied to generational differences in both disclosing and experiencing mental health issues? Have more recent public health and educational campaigns allowed youth to feel more comfortable in disclosing mental health issues to other youth compared to adults who grew up in a culture that was blind at best, hostile at worst to the topic of mental illness?

Table 4.6. Top reasons for which young carers provide care to relatives and non-relatives, 2012 (Canada).

	PRIMARY CARE RECEIVER			
Reasons	**Family**	**Friend**	**Neighbour**	**Co-worker**
First	Aging / old age (33%)	Mental Illness [1] (36.5%)	Cardiovascular disease [2] (37.7%)	Back problems (88%)
Second	Cancer (10%)	Developmental disability (12%)	Aging / old age (29.6%)	Joints problems (12%)
Third	Cardiovascular disease (8.1%)	Injury due to accident (8.5%)	Arthritis (8.9%)	

Source: Statistics Canada, General Social Survey, 2012.

1. For example, depression, bipolar disorder, manic depression or schizophrenia.
2. Including angina, heart attack, infarction and hypertension.

Or, is this pattern reflective of national polling data that show Canadian youth are the hardest hit by depression and other mental well-being concerns? Research indicates that as age decreases, the risk of developing a mental health issue increases, with 14% of baby boomers deemed “high risk” compared to 35% of Gen Xers and 53% of millennials (Chai, 2015). Future research will need to probe this area in more depth.

Directing our attention to the category of neighbour also reiterates the dual impact of an aging population and more recent shifts to home-care models of health and social service delivery. With almost 40% of youth-based care provided in the context of aging (29.6%) and arthritis

(8.9%), the impact of an increasing number of older persons living alone in communities to *age in place* becomes even clearer.

4.4.3 The role of gender

At the outset of this analysis, results revealed the combined care gender imbalance of 47:53 (male-female) in 2012. By cross-tabulating gender with a selection of additional variables, Table 4.7 provides a more thorough picture of how gender impacts decisions surrounding care.

First, females provide the vast majority of care due to long-term illness and disability (66%) yet males provided the large majority of non-relative care (60%).

Second, and corroborating the census analysis results, married (97%) and common-law (74%) females provide the overwhelming majority of all care within their marital status grouping, with the least gender imbalance found among single, never married youth (52%).

Third, the interplay of gender and level of weekly caregiving reveals results consistent with the 2006 census data, with females seeing their proportion of care generally increase with each care level. Alternatively, male young carers experience a decreasing burden of care with each increasing care level.

Fourth, and dissimilar from the census results, is the lack of an age-progressive feminization of caregiving. As youth age, the proportion of female young carers slightly decreases while the male proportion slightly increases. This also explains why, unlike the census results found in Figure 4.2, the interplay of gender, age and level of weekly care (results not shown) did not produce such a consistent pattern of age-progressive feminization of care.

Fifth, the range of care tasks provided by youth also reveals important gendered differences. Specifically, female youth provide the majority share of care for all but two types of care: banking and financial assistance (51%) and house maintenance or outdoor work (55%).

Table 4.7. Select characteristics of youth-based caregiving by sex, 2012 (CANADA)

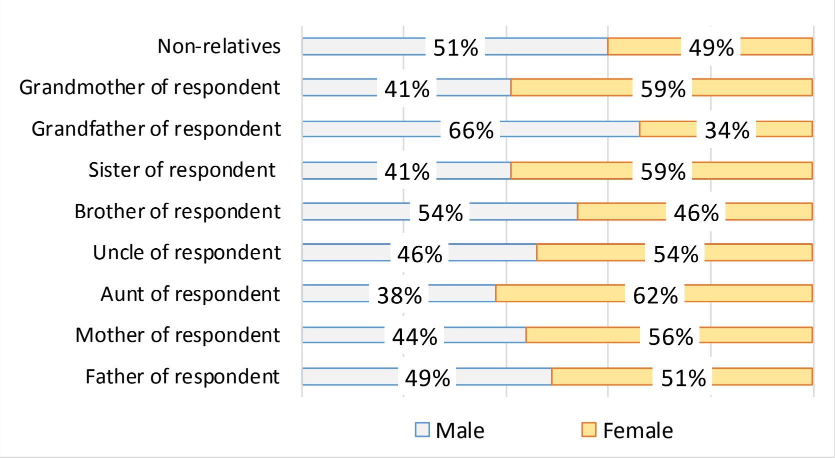
	SEX		**Total**
	Male	Female	
Context of care provision	*(Percentage)*		
Long-term illness or disability	34	66	**66**
Problems related to aging	49	51	**34**
Relationship between caregiver and care receiver			
Relative	46	54	**84**
Nonrelative	60	40	**16**
Marital Status			
Married	3	97	**1.8**
Common-law	26	74	**4.3**
Divorced, separated, widowed	27	73	**0.4**
Single, never married	48	52	**93.5**
Hours of care per week			
<5hrs	50	50	**63**
5-14hrs	42	58	**22**
15-29hrs	47	53	**8.5**
30+hrs	32	68	**6.5**
Age			
15 to 17	46	54	**29**
18 to 19	46	54	**18**
20 to 24	48	52	**53**
Types of care provided ±			
Meal preparation, cleaning, laundry	42	58	**66.8**
House maintenance or outdoor work	55	45	**62.2**
Transportation	44	56	**61.9**
Medical procedures or treatments	42	58	**21.2**
Personal care (e.g., bathing, dressing)	23	77	**17.2**
Scheduling care-related tasks	40	60	**13.7**
Banking, bill paying or managing finances	51	49	**8.8**

Source: Statistics Canada, General Social
± Refers to last 12 months
N= 1,253,326 (Weighted sample)

These two tasks have also been shown to be gendered among the adult-based Canadian caregiving population (Sinha, 2013). Moreover, the most drastic gender differentials were found for 'personal care' (e.g., bathing, toileting and dressing), with female youth providing 77% of all such care. These findings have also been corroborated among adult caregivers, where sons have been shown as more likely to substitute in some activities compared to others based on cultural assumptions about what constitutes gender-appropriate behaviour (Spitze & Logan, 1990; Matthews, 1995). Persisting perceptions of women as "nurturers" has been shown to explain men's reduced involvement in certain types of assistance, especially personal care (Campbell & Martin-Matthews, 2003; Davidson, Arber, & Ginn, 2000).

Sixth and last, gendered patterns were shown to impact decisions surrounding who to provide care for, with young carers more likely to provide care to someone of their own sex. By focusing on the top caregiving dyads (Figure 4.3), we see that the most obvious gendered patterns involve care provided to grandparents, especially grandfathers, followed by aunts. The only two instances where females provide the majority of opposite-sex familial care is with uncles and fathers.

Figure 4.3. Relationship of care receiver to caregiver (respondent) by sex, 2012 (Canada).



Source: Statistics Canada, General Social Survey, 2012.
Note 1. N= 1,087,596 (weighted sample)

Non-relative caregiving is not as clear cut as we do not necessarily know the gender of the coworkers, friends and/or neighbours afforded to us by the more gender-explicit familial terminology. More broadly, we know that males hold the slight majority (51%) of non-relative care as per Figure 4.3 but in order to see how gender impacts choices surrounding non-relative care, we must also factor in the sex of the care receiver.

As Table 4.8 shows, while males held the majority of all non-relative care, their involvement varied by the type of relationship. The most drastic concentration of male-driven non-relative care was for co-workers, where they provided 100% of all care followed by neighbours (68%) and close friends (54%). Generally, gender played a much stronger role in influencing the choice of care-receiver among non-relatives than relatives, with the most pronounced effects seen among neighbours and co-workers.

Table 4.8. Provision of relative and non-relative care, by sex of young carer and sex of care-receiver (percentage), 2012 (Canada).

Relationship between caregiver & care receiver	**SEX OF CAREGIVER**	**SEX OF CARE RECEIVER**		***TOTAL***
		Male	*Female*	
Relatives	Male	*55*	*42*	*46*
	Female	*45*	*58*	*54*
	Total	*100*	*100*	*100*
Close friends	Male	65	36	54
	Female	35	64	46
	Total	*100*	*100*	*100*
Neighbours	Male	83	28	68
	Female	17	72	32
	Total	*100*	*100*	*100*
Co-workers	Male	100	0	100
	Female	0	0	0
	Total	100	0	100

Source: Statistics Canada, General Social Survey, 2012. N=1,223,949 (Weighted sample)

4.5 CHAPTER CONCLUSION

Although the Canadian census possesses distinct conceptual and methodological limitations that prevent the full capture of all those potential young carers, it still represents the best and only source to examine the minimum rates and growth of youth-based unpaid caregiving across all of Canada over 1996 to 2006. From this first analysis, various important trends were uncovered. First, it importantly demonstrated that Canadian young carers represent one of the largest global young carer groups, with 1.18 million youth between the ages of 15 and 24 providing some level of unpaid care in 2006, representing a 13.5% increase over 1996–2006. Of these, 20,792 youth aged 15 to 24 provided upwards of 20 hours of unpaid care per week to seniors with another 45,356 youths providing an even greater level of 30 or more hours of weekly care to children. Second, important gendered patterns were revealed. Females not only accounted for the majority of young carers (corroborating U.K. data) but they experienced an increasing feminization of care as they aged (corroborating Australian data), the differences of which were most acute at the highest care levels. Third, the disproportionate share of caregiving by youth in Northern Canada and the impact of marital status (specifically, married/common-law) in promoting female youths increased involvement in unpaid caregiving was clear and unambiguous.

While the census data include a range of young carers not necessarily captured by the GSS and other sets of official country data used to pull young carer statistics, it opens our eyes to a cohort of young carers traditionally overlooked in the existing literature. To be exact, it underestimates unpaid care provided in the context of chronic illness or disability while overestimating unpaid care provided to siblings in the context of parental absence and/or familial fragility. Due to the structure and sampling restrictions of the unpaid care questions, however, the census unfortunately eliminates a large subset of young carers traditionally focused on in the wider literature, which is youth under the age of 15 years and youth providing care to parents (or any other adult).

The GSS, on the other hand, makes up for half of this oversight by counting care provided to persons of all ages, not merely children and/or seniors. Including the qualifier that caregiving must be delivered in the context of aging and/or long-term illness or disability further renders the GSS data comparable to other official sets of country statistics, mainly Australia and the United Kingdom. Lastly, cycle 26's focus on "Caregiving and Care Receiving" provides a much more detailed picture of caregiving, affording insights into the incidence and level of informal caregiving as well as crucial information relating to the relationship between caregiver and care receiver, the types of care tasks provided and various consequences of caregiving. The failure to enumerate youth under the age of 15 years, combined with the omission of Northern Canada from its sampling frame, however, render it an imperfect data source that cannot be benchmarked against the census to produce nation-wide estimates.

From this second analysis, it was discovered that the number of Canadian young carers far outstripped the 175,000 documented in the United Kingdom (Becker, 2007) and the 139,891 documented in Australia (Cass et al., 2009, p. 26). Over 27.4% of all Canadian youth aged 15 to 24 (1.25 million) provided some level of unpaid caregiving due to aging or long-term illness or disability in 2012. Additionally, important and previously unreported insights into the nature of youth's caregiving were discovered. Canadian youth providing care in the context of long-term illness, disability or aging were shown to provide a greater level of care compared to those providing more generalized *child* and *senior* care (as discovered via the census analysis). In 2012, over 185,000 youth provided 15 or more hours of weekly care compared to the just over 100,000 who provided 15 or more hours of child care and nearly 21,000 who provided 20 or more hours of senior care in 2006. Given the shifts from hospital to home care and the privatization of previously publically available health services, which disproportionately affects caregivers of chronically ill and disabled persons, it is understandable why this cohort of caregivers experiences a heavier care burden. Those youth captured by the census are more likely to provide added sibling and supplementary senior care in the context of familial fragility and/or parental absence.

The GSS data also revealed that despite the majority of youth providing care to relatives, particularly grandparents, over 11% (144,828) of youth were providing care to non-relatives. Care provided to close friends, as an example, represented the fifth largest category, surpassing the combined care provided to brothers and sisters. Moreover, unlike the care provided to relatives and other non-relatives, unpaid care provided to close friends was done so predominantly in the context of mental illness. With traditional young carer research focusing primarily on familial care, these results highlight the need to expand traditional definitions of "young carer" to account for a wider range of caregiving dyads.

Finally, the GSS analysis reiterated the continued power of gender and marital status in decisions surrounding care. Among the married (1.8%) and common-law (4.3%) youth caregivers, females continued to provide the vast majority of care compared to males, with the gendered differences the weakest among single, never married youth caregivers. Gender also had a clear role in the choice of care receiver, with youth generally more prone to care for an individual of the same sex. Gender also impacted the types of care tasks provided, Male youth were overrepresented in male-typed tasks including household maintenance and financial assistance while female youth were overrepresented in the provision of personal care. These findings validate research among adult caregivers.

When analyzed together, the census and GSS paint a clearer picture of the overall nature of youth-based caregiving across Canada and the differences among its two qualitatively different respondent pools. With the census better able to capture informal care provided in the context of parental absence tied to familial fragility, and the GSS better able to capture informal care provided in the context of chronic illness and/or disability, this two-fold analysis casts a broader net of young carers not possible by focusing on either data source alone. By working with both datasets and comparing their respective strengths and weaknesses, this research uncovered important insights into areas for improvement for future care-based survey instruments. The most important of these include the need to survey youth of all ages but also over a broader, less context-specific range of circumstances. Their respective differences aside, both highlight the impact of not only gender and marital status on decisions surrounding youths unpaid care and support but also the impact of our aging Canadian population.

What this chapter ultimately reveals is that the current invisibility of young carers in Canada is not attributable to their low prevalence but to the larger public oversight of youth as both providers *and* receivers of care. Acknowledging that young carers' duties tend to remain unrecognized and unspoken of, certainly in their social circles, the potential exists for a slew of educational, material and health-related consequences to go unnoticed and undocumented, consequences for which youth are ill-equipped to handle. With this in mind, the next chapter will turn to a first-hand account of youth-based caregiving from the perspective of young carers residing in Southern Ontario.

CHAPTER FIVE

The benefits and challenges of youth-based caregiving: A first-hand account into the lives of young carers.

5.1 INTRODUCTION

To date, only two Canadian studies exist to provide first-hand accounts of youth-based caregiving, both employing focus groups to explore the needs and experiences of children impacted by chronic familial illness. The first explored the experiences of children providing care and support in the context of Frontotemporal dementia (FTD), a neurodegenerative illness with early onset (before the age of 65) and with a more rapid decline than Alzheimer’s disease (Nichols et al., 2013). The second explored the experiences and needs of children impacted by parental multiple sclerosis (Toporas, 2005). This research will add to the Canadian literature by providing an in-depth account of the day-to-day lives of young carers who are presently (or were previously) receiving support from a dedicated young carer’s program. While the interviews probe various aspects of youth’s caregiving, from the level and types of care provided to the nature of their care relationships, special attention is paid to its benefits and challenges.

5.2 THEORETICAL FRAMEWORK

The global young carer literature has documented a range of costs and benefits that are often congruent with those found in the adult-based caregiving literature. While important differences exist, centering on the age of the carer, the care they provide may still be located within key frameworks grounded in feminist political economy.

Daly and Lewis's (2000) social model of care offers a useful paradigm with which to understand both the central tenets of care-work but also its multi-dimensional nature, including the state, market and voluntary sector forces that play a role in increasing or decreasing the level of informal caregiving required by family members. Applying this framework to youth allows us to see how the caregiving they provide satisfies the three central characteristics of Daly and Lewis's model: (1) that the care provided is labour; (2) that the labour provided is done so within a normative framework of obligation and love, and (3) that the labour provided is an activity which carries pecuniary and non-pecuniary costs. By viewing care as labour that occupies time, which could otherwise be available for participation in education, training, employment, and social activities, this framework can be used to assess how potential costs incurred by youth's caregiving (e.g., interrupted education and labour force participation) results in a unique *Young Carer Penalty* - a term coined by this study.

Pursuant to this, England and Folbre (1999) and Folbre (2002, 2012) have shown that the hours of work (paid and unpaid) have implications for the personal health and development of human capabilities, resulting in a unique gendered care penalty – a concept coined for the sacrifices that adult women make when performing care work. Here, the provision of care work is seen as limiting a person's ability to compete with those who do not have to provide such care, which leads to distributional struggles relevant to gender roles in that women perform the overwhelming share of caring activities. This, in turn, renders women in an inferior position to build on their human capital, defined by Folbre (2012) as:

> The endowment or accumulation of skills that improve productivity and are likely to yield a future rate of return, whether in the labor market (in the form of higher wages), other markets (such as a payoff to entrepreneurship), or in other domains of life (including, for instance, improved health or more successful children). (p.282)

Numerous studies substantiate the feminized care penalty among Canadian women[26]. One such study –the 2011–2012 National Survey Study on work-life conflict – examined the challenges faced by adults who juggle paid employment, unpaid caregiving, and for some respondents, childcare. Surveying close to 8,000 Canadians, the researchers show that not only are the majority of employed adult caregivers women (70%) but that twice as many women than men provide elder and child care simultaneously and three times as many women than men provide elder care exclusively (Duxbury & Higgins, 2012a, p. 58). Additionally, compared to employed male caregivers, employed female caregivers experience greater negative consequences as evidenced by less time for self, less time for sleep, loss of personal energy, reduction in social life, higher absenteeism at work, higher levels of stress and depressed mood, and less support received from their partners in their caregiving (Duxbury & Higgins, 2012a).

While such research makes a convincing case for the care penalty as it relates to adult women, we do not know enough about how the care penalty impacts youth who are assuming the substantial care work characteristically performed by their mothers. Duxbury & Higgins similarly acknowledge this grey area after completing their third national study on work-life balance in Canada. While focusing their attention to employed adults aged 18 years and over, they nevertheless point to the fact that “most research focuses on older workers (Statistics Canada's General Social Survey, for example, focuses on workers 55 years of age or older)” which omits a clearer understanding of the issues faced by younger caregivers (2012, p. 10).

---

[26] See Armstrong & Armstrong, 1994, 1999; Armstrong & Kits, 2001; British Columbia Law Institute, 2010; Duxbury, Higgins, & Schroeder, 2009; Duxbury & Higgins, 2012; Grant, 2004.

Before we adopt adult-based theories of care to explain the experiences of young carers, additional consideration is required as to their transferability. First, adult-based theories naturally leave out developmental impacts given that care is provided well after adolescence has passed, with adults arguably better able to exercise control over their care work due to added financial, legal and maturational advantages. Adults have had a head start at building their human capital and may not necessarily suffer the same impacts to their future security and well-being compared to youth, who are in the midst of this process. Adults are also better positioned to draw support and information from other adults who have likely had experiences with providing care and support to family members. In this sense, adults can be said to have a caregiver advantage whereby their age provides them: (1) added financial and intellectual resources with which to manage, and even contract out or seek assistance with, some of their caregiving; (2) added flexibility in leaving their households on a long or short-term basis as autonomous adults unbound by the legal constraints youth encounter as "minors"; (3) recognition of their caring role as an acceptable and normative component of adult life, and (4) fewer long-term impacts to their subsequent human capital due to the later onset of their caregiving. Indeed, the impact of youth taking on developmentally inappropriate and overly burdensome tasks, essentially pseudo-parental roles, is something unaccounted for by traditional sociologically-grounded care theories.

Where we do find more targeted information on age-based caregiving differentials is in the young carer and parentification literature. In Australia, state commissioned research on young carers highlights how caregiving youth under the age of 25 have relatively high levels of unemployment, lower rates of labour force participation, and higher rates of receipt of government income indicative of lower personal income (Bittman, Fisher, Hill, Thompson & Thompson, 2004; Carers Australia, 2002). The probability of participation in employment among Australian youth aged 15 to 24 reveals an additional gendered penalty. Here, the probability of participation in employment increases for male young carers compared to their non-caregiving male counterparts while the opposite occurs for female young carers compared to their non-caregiving female counterparts (Cass et al., 2009). In the United States, young carers aged 8 to 18 years were shown to have a higher likelihood for displaying antisocial behaviour at school as evidenced in the following areas: bullying and acting mean towards others, disobedience and trouble getting along with teachers, and associating with kids who get in trouble (National Alliance for Caregiving/United Hospital Fund, 2005). One in five U.S. young carers also cite missing school or afterschool activities due to their caregiving and 15% indicate that it keeps them from doing school work (National Alliance for Caregiving/United Hospital Fund, 2005). In the United Kingdom, research suggests that young carers perform badly in the educational system, with over a third of secondary school age young carers missing school or having educational difficulties (Dearden & Becker, 1998). Educational difficulties at an early age can have a negative effect on later education, training or employment and make the transition into adulthood more difficult for these youth (Dearden & Becker, 2002a).

The parentification literature, borne out of psychology, provides additional evidence as to the social and emotional impacts incurred by children and youth when taking on responsibilities that exceed their ability (Minuchin, 1967). The concept of the *parentified* child refers to children who are expected to fulfil the parental role in the family, often acting as a parent to other children or to their parents. Also referred to as role reversal, these children are often discussed in studies of children of alcoholics, sexual abuse, marital conflict, and divorce (Barnett & Parker, 1998). First coined by Minuchin, Montalvo, Guerney, Rosman, & Schumer (1967) to refer to children who assume parental responsibility in the home as a result of economic and social conditions, the concept has been expanded to include a process of ‘parentification’ (Boszormenyi-Nagy & Spark, 1973) that illustrates how all relationships, including healthy ones, contain components of caregiving underlined by patterns of relating that only become problematic once they become excessively burdensome to the child. This opens up the possibility that parentification (like caregiving) may have either positive, negative, a combination of positive and negative, or no effects at all depending on the child’s position on a care continuum from minimal to maximal.

By focusing on the developmental impacts on a parentified child’s identity, behavioural health and personality, parentification researchers have shed light on important age-based differentials with excessive or burdensome caregiving. First, West and Keller (1991) illustrate how a form of “compulsive caregiving” can arise among parentified children, triggered from the initial role reversal in the parent-child relationship. Here, the reversal of caregiving behaviours from a child to a parent is seen as altering the child's attachment system, leading to dysfunctional relationships in later life due to the individual losing any ability to express need or ask for care while retaining a “pervasive, unsatisfied neediness and longing for care” (West & Keller, 1991, p. 431). Valleau, Raymond and Horton (1995) similarly reveal how parentified children continue to adopt caretaking roles with other adults in later life due the development of a self-concept adapted to the caring task, a phenomenon referred to as the “caretaker syndrome”. Comparable evidence among former young carers, via retrospective studies with adults, reveals a similar extension of their caregiving roles within extra- and future familial relationships due to the belief that they had been “trained” to do so in their childhood (Charles, Stainton & Marshall, 2012a, p. 14).

Second, behavioural, health and personality effects observed among parentified children have also been shown to mirror those found in the global young carer literature. These range from increased sleeping disturbances, depression and anxiety (Aldridge & Becker, 1993; Fullinwider-

Bush & Jacobvitz, 1993; Jacobvitz & Bush, 1996; Salter, 1999), poorer school performance and difficulties maintaining healthy social relationships with peers (Aldridge & Becker 1993); increased aggression and delinquency (Aldridge & Becker 1993; Johnston, Gonzales & Campbell 1998); feelings of loneliness, guilt, and isolation (Dearden & Becker, 2002a; Salter, 1999) as well as self-harm, disordered eating and substance misuse (Cree, 2003).

Positive outcomes have also been associated with early caregiving. An increased resilience in handling stress and coping with adverse situations is one such positive consequence discussed in both the young carer and parentification literature. Caregiving youth have been shown to develop and utilize a range of constructive coping strategies that include positive appraisals of their situation, the development of practical life skills and an increased sense of pride and mastery (Cassidy, Giles & McLaughlin, 2014; Clay, Connors, Day, Gkiza & Aldrige, 2016; Joseph, Becker, Becker & Regal, 2009; Packenham & Bursnall, 2006; Packenham, Chiu, Bursnall, Cannon, 2007) and the proactive seeking out of social support from both familial (extended and immediate) and community sources (Cluver, Operario Lane, Kganakga, 2012; Skovdal & Daniel, 2012; Skovdal, Ogutu, Aoro & Campbel, 2009). Additional positive consequences documented in the literature include: added insight into illness and hardship, appreciation of life, health gains, spiritual growth and positive changes in life priorities and personal goals (Charles, Stainton & Marshall, 2010a; Nichols et al., 2011; Pakenham & Bursnall, 2006); a heightened sensitivity to the needs of others and a corresponding increased level of altruism and compassion (Becker, 1995); a meaningful and heightened closeness with the care-receiver and/or other relatives (Aldridge & Becker, 1993; Carers Australia, 2002), and an enhanced view of themselves as worthwhile, competent and independent individuals (Carers Australia, 2002; Early, Cushway & Cassidy, 2007; Skovdal, Ogutu, Aoro & Campbell, 2009; Skovdal & Ogutu, 2009; Smyth, Blaxland & Cass, 2007). Together, these benefits can result in the development of "positive carer identities" in which the young carer depicts their role as caregivers in a positive light, often tied to local cultural understandings of duty and childhood and the positive perceptions acquired through participating in a socially valued service (Andreouli, Skovdal & Campbell, 2013, p. 1039). For these reasons, my interviews with young carers will probe both the positive and negative consequences of caregiving.

5.3 PROCEDURAL POSTSCRIPT AND RESULTS OVERVIEW

A total of fifteen youth aged 15 to 19 were included in this first qualitative data sample. Two Focus groups (n=10, n=4) were conducted with 14 young carers aged 15 to 19 years residing in Southern Ontario, each lasting roughly 90 minutes in duration. One solo interview was also conducted with an additional youth, which lasted roughly 60 minutes in length. Youth were contacted through purposive sampling via their past or current involvement with two of the three current young carers programs in Canada (i.e., the YCP in Toronto and the YCI in Niagara-Haldimand region). A short, post-interview survey was also provided for participants to complete as a method of concurrent triangulation that aimed to complement the group interview data while highlighting any discrepancies. A breakdown of the socio-demographic characteristics of the sample participants and their care situations is included in Table 3.1 (Chapter Three). The full list of questions asked of respondents is also included in Appendix C.

Subsequent thematic data analysis reveals four key thematic areas pertaining to: (1) high versus low level caregiving; (2) recognition versus rejection (3) positive versus negative consequences of caregiving, and (4) approach versus avoidant coping. The classification of themes presented as dichotomous sets reveals the often complex nature of caregiving wherein the presence of polarities exist along a continuum with gradations between the poles.

5.4 HIGH VERSUS LOW LEVEL CAREGIVING

The first theme juxtaposes youth's involvement in both "normative" adolescent roles and "parentified" roles. Young carers exhibit both age-appropriate, low-level caring roles that can be seen as a natural and normative part of adolescence while maneuvering in and out of high-level, episodically parentified roles that hamper their short and long-term development. As Becker (2009) reveals, children's caregiving can be viewed along a continuum, with all children being involved in some aspects of caring throughout childhood, but with a much smaller proportion involved in ongoing, substantial, or primary caregiving roles, often from an early age, and which in some cases are associated with serious negative outcomes. By focusing on a degree of caregiving expressed in terms of both the hours of caregiving per week (i.e., low, medium, high) and the types of care tasks provided, young carers will be shown to be a diverse group who provide a wide range of tasks at differing levels.

5.4.1 Levels of care

On one end of the continuum are those low-level caregiver dynamics that can be seen as representing a form of constructive childhood development. As is the case with a large minority of participants in this sample, youth provide caregiving that is not burdensome or excessive. On the other hand, close to half of the participants in this sample provide inarguably burdensome and restrictive caring roles that for many amounts to the equivalent of a part or even full-time job.

The creation of care levels is a difficult and subjective task. Most existing studies simply present the basic descriptive statistics surrounding care contributions, such as the average or median hours of unpaid care provided per week. This study provides a benchmark for determining numerically-based levels of care for youth that are guided by the concept of role overload. The concept of role overload has been an area of growing scholarly interest over the past two decades, stemming from changes occurring with the "decade of change" in the 1990s (see Chapter Two, section 2.1.4). Researchers have shown that role overload has undergone steep increases over this period, a finding consistent with anecdotal and media reports illustrating Canadians are feeling increasingly caught in a time crunch and/or pressed for time (Duxbury & Higgins 2001, 2012; Canadian Index of Wellbeing, 2010). For Duxbury & Higgins (2011, 2012), role overload occurs when the total demands on time and energy associated with the prescribed activities of multiple roles are too great to perform the roles adequately or comfortably (Duxbury & Higgins, 2001). In their research, two key role types that adults must contend with are that of "employee" and "family member", with role overload occurring when either role begins to interfere with the comfortable or adequate performance of the other.

In this study, the concept of role overload is modified from that used by Duxbury and Higgins (2001, 2011, 2012) to more appropriately apply to youth populations. Specifically, by substituting the main adult-centered role of *employee* for a more appropriately youth-centred role of *student,* we may determine how the average hours dedicated to each of these main roles can interfere with the demands of the caregiver role, and vice versa.

In 2007, a Statistics Canada report on the "busy life of teenagers" revealed the average hours spent per day for the population of youth aged 15 to 19 (Marshall, 2007, title). For such youth, school days are comprised of a combination of roughly seven hours of school (classes, meetings, etc.) and 2.3 hours of homework, paid work and housework (Figure 5.1). On non-school days, youth aged 15 to 19 spend an additional three hours on homework, paid work and housework per day (Figure 5.1).

Figure 5.1: Statistics Canada: Average hours spent per day for the population aged 15 to 19 (1986 to 2005).

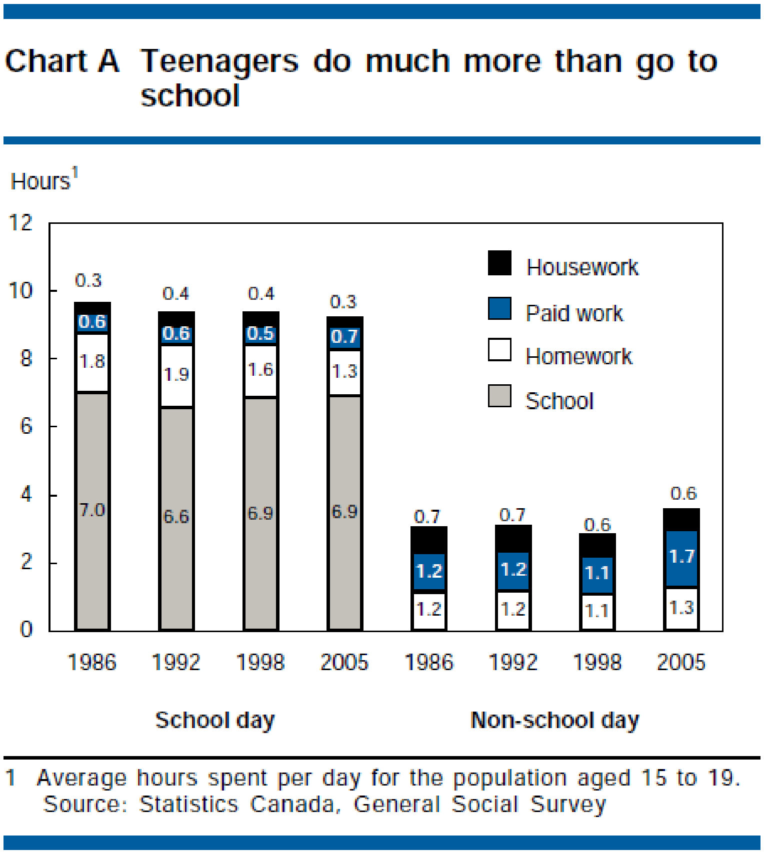


Chart A Teenagers do much more than go to school

1 Average hours spent per day for the population aged 15 to 19.
Source: Statistics Canada, General Social Survey

Source : Marshall, K. (2007). The busy lives of teens. Perspectives on Labour and Income, 19(2), 5-15.

At the time of this report, provincial school boards had only begun to stipulate mandatory community service requirements for high school graduation, with a gap left in these estimates for that additional time requirement. The most recent national data for volunteer activity of young Canadians aged 15 to 24 reveals that this age group are more likely to volunteer than Canadians in most other age groups. Focusing in on those Canadian youth aged 15 to 19 (the same age range included in this sample of young carers), 66% are shown to provide an average of 115 hours of volunteer work over the course of the year (Vezina & Crompton, 2012). Although the incidence of daily participation in volunteer work is too small for a detailed analysis of its daily provisioning (Marshall, 2007), this amounts to roughly 20 minutes per day[27]. Add this to the existing seven hours a day for school, 2.3 for homework, paid work and housework (for non-caregiving youth), and 9.5 hours of the average school day for a Canadian youth aged 15 to 19 is accounted for. Added caregiving duties aside, it is understandable why reports warning of the overscheduling of Canadian teenagers and the issues experienced when they lack down time to relax and unwind have emerged (Canadian Paediatric Society's Adolescent Health Committee, 2008). With roughly 10 hours of a youth's average school day already accounted for, it becomes clear that the stereotype of lazy, nonchalant and lounging teenagers fails to hold up in the face of the heavy load that many indeed carry (Marshall, 2007). This load exists for the average youth, irrespective of whether they take on a family caregiving role and irrespective of any respite or down time dedicated to social or extracurricular activities.

In Canada, most high schools start as early as 8:00 am and last roughly until 3:30pm. Research also shows that Canadian teenagers require between 9 to 10 hours of sleep per night (Canadian Paediatric Society, 2008). This leaves youth with a window of time between 4:00pm to 9:00pm (factoring in roughly 30 minutes to commute back home from school) within which to complete their three hours of documented volunteer, paid, house- and homework before surrendering for the suggested (minimum) nine hour sleep allotment. With this in mind, three care categorizations based on hours of unpaid care provided per week are presented as follows: A *low* degree of care is defined as the provision of up to 10 hours of unpaid caregiving per week; a *medium* level represents between 10 to 20 hours of unpaid weekly care, and a *high* level represents

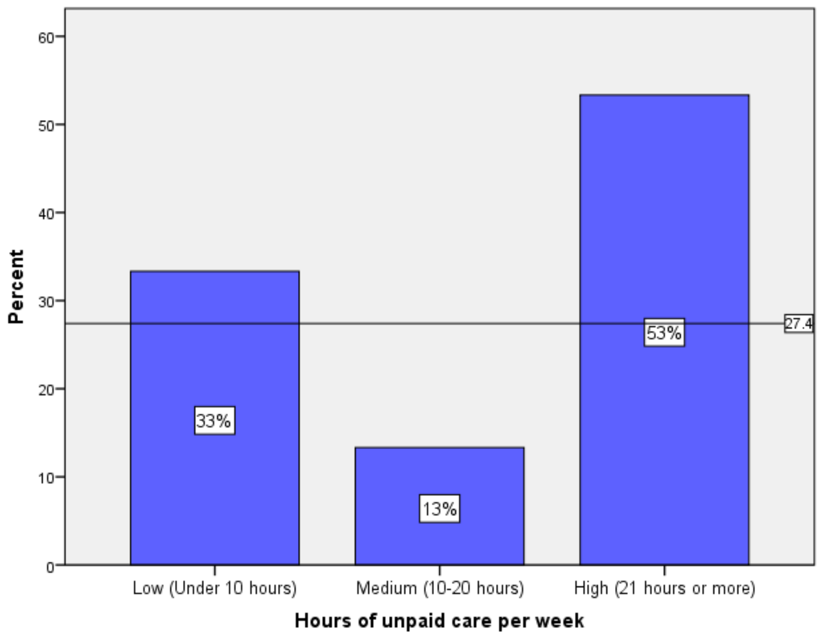
---

[27] 115 hours = 6900 minutes per year, /12= 575 minutes per month, /4= 143.75 per week, /7= 20.5 mins per day.

the 21 or more hours of unpaid care provided per week. These numerical benchmarks are justified when accounting for two additional considerations: the time that the typical youth require for sleep in a given day and the average time dedicated to their student role. Accordingly, those youth providing between 60 to 90 minutes of caregiving per day (amounting to a low degree of care) may not face a serious disruption to the time constraints required to complete the three hours of volunteer, homework and paid work youth perform on average in a typical school day. Those providing between one and a half and three hours per day (medium) likely experience moderate role overload given that they are beginning to maximize their available window of daily 'free' time outside of school hours (i.e., the 4:00pm to 9:00pm after-school period). Those providing greater than three hours per day (high) inarguably face the greatest role overload in that the available time to theoretically satisfy their educational and family obligations has now run out.

Classifying the intensity of youth's caregiving along these three rough categories reveals a bi-modal distribution with sample participants providing predominantly low or high levels of caregiving.

Figure 5.2 : Level of weekly caregiving provided by young carers (N=15)



As Figure 5.2 shows, 33% (n=5) of young carers in this sample provide low-level caregiving while a greater 53% of sample participants (n=8) provide high-level, time-intensive caring roles that occur daily, for multiple hours each day. The mean score of 27.4 hours and coinciding standard deviation of 23 hours explains the wide variation of scores and the resulting bi-modal distribution. Research on adult caregivers corroborates the presence of a bi-modal distribution in terms of the level of weekly unpaid caregiving provided per week. Duxbury, Higgins and Schroeder (2009) found that the two largest groups of employed Canadian caregivers were those providing 40 to 60 hours per week to their *dual* work and unpaid caregiving roles (37%) juxtaposed with a quarter who were providing greater than 100 hours per week (p.9).

Indicative of the high-level caregiving provided by youth in this sample are the following first-hand accounts:

> P1: In a typical day, maybe like 6 hours. (Female, age 15)
>
> P2: Not really sure, just all day…it's not like a set amount of time…just all throughout the day, just always, basically (Female, age 15)
>
> P3: Most of the day…so I'd say 12 hours (Male, age 18)
>
> ***Moderator: 12 hours? So most of the day when you are not at school?***
>
> P3: Well ya…or sometimes I just don't go to school.

These accounts also reveal the difficulty that many participants experience when attempting to count care. The lack of precision in determining such daily, weekly, monthly and estimates can be attributed in part to three issues. First, memory recall errors that are likely to occur in the absence of more precise tracking protocols. Time-use diaries, as an example, can help reduce these errors by asking youth to detail the total time spend undertaking various tasks in a specified period, usually 24 hours (Hunt & McKay, 2015). Second, the wider confusion surrounding the question of what counts as care and what counts as merely ordinary exchanges of family life can obfuscate precision in tallying care estimates, as well as the reliability of those estimates. Third, many young carers in this sample note the "on-call' nature of their caregiving, contingent on the frequently fluctuating needs of their receiver(s). This nonstandardization of care tasks over a longer portion of the day can produce memory confusion, hampering the ease with which young carers (and all caregivers) mentally calculate such aggregated figures.

Finally, although the sample size limits precision in determining the extent to which factors such as gender, race, income or household structure impact level of care, evidence from this specific sample did suggest mediating roles for key socio-demographic characteristics traditionally outlined in the adult-based care literature. Most of the sample participants were female despite a purposively extended eight-month period of recruitment in order to locate the three participating males. Indeed, additional female young carers who wished to participate in the study were turned down in order to include male young carers in the sample.

This gendered finding is consistent with national survey data demonstrating that female young carers outnumber male young carers in Australia (Cass et al., 2009) and the United Kingdom (ONS, 2013). While the statistics likely reflect the persistent overrepresentation of women in such caring roles, they also likely underrepresent male young carers due to the conflict boys experience when openly discussing or recognizing their care contributions. In Eley's (2004) research on Scottish young carers aged 10 to 17 years, boys were found to shy away from discussing their care work and instead would "bottle" up their anger or stress in the absence of acceptable same-sex peer outlets. As one participant reveals, "guys…they don't have that sort of friendship, it's you know having a couple of lads talking about girls but that's about it…" (Eley, 2004, p.68). The gendered reticence to sharing information about their caregiving due to the presumed violation of expected gender roles makes it more difficult for young males to get recognition and receive dedicated supports as carers. It is also helps explain the added difficulty experienced when trying to recruit eligible males to participate in this study.

Gender forces are also at play regarding the degree of care provided. With the exception of one male young carer who was an only child in a single parent family, female young carers were shown to provide a greater level of weekly care. This finding validates global research revealing that girls have greater care-based expectations placed on them relative to boys and undertake more of the caring *even if* there are other young males available in the household (Becker & Becker, 2008; Eley, 2004). As a prime example afforded from the presence of a pair of siblings in my sample (one female, aged 15 and one male, aged 16), accompanying survey data was able to confirm that it was the female sibling who provided more care per week and had been doing so for a longer period of time, despite being the younger sibling. Gender thus influences both the provision of care and the level of care provided with conflicting evidence existing only in situations in which the sibling was an only child and if there were no other available females left in the household to provide caregiving.

Economic forces can also influence the level of care provided. Young carers note how additional funds can provide added flexibility surrounding their caregiving, the awareness of which increases with age as evidenced by reports from the more senior participants in the second focus group. Age aside, when asked whether youth think that having more money can provide them with greater flexibility, all participants agree. As they see it, more money brings a greater ability to purchase supplementary services such as household cleaning and necessary aids such as stair lifts. As one participant explains:

> I am hoping my music career will take off as a singer so I can afford to change things for them, for example have healthier food in the house and hire a healthy cook and things like that … (Female, age 17)

Another participant indicates her desire to “hire a maid to clean [and] manoeuver my mom around” (mother is a double amputee). At the same time, young carers are not interested in fully contracting out their care. Added financial resources are discussed only as a supplementary aid. As one young carer reveals: “I wouldn’t hire someone to do everything, just some things”. Young carers simply want some relief from the difficult tasks and long hours of the care work they endure.

Finally, the attendant post-focus group survey included a question about household income as a method of triangulation. However, the majority ‘Don’t Know’ responses render their usability null and void. Despite income questions generally known to possess greater measurement error via misreporting (Tourangeau & Yan, 2007), this higher level of non-reporting among this sample is likely a reflection of youth simply not knowing or having access to such family financial information. What this also highlights is the need to have parental involvement in future young carer research in order to attain accurate financial information and other related socio-demographic information that can assist with prospective research and policy recommendations.

5.4.2 Types of care

Young carers demonstrate a wide range of routine, instrumental and personal care tasks.

Personal care tasks that young carers provide include dressing, showering/bathing, the administration of medicines and assistance with other activities of daily living (ADL's) such as moving around the house and providing assistance with putting on and removing prosthetic limbs (Duxbury & Higgins 2009; Lum, 2008). To differentiate ADLs from somewhat less intensive and personal activities such as grocery shopping and housekeeping, the term "instrumental activities of daily living" (IADLs) can be used (Duxbury & Higgins 2009, Lum, 2008). Instrumental tasks performed by young carers include sibling care, cooking and cleaning duties and translation for parents who do not speak English. Among this sample of participants, levels of care were often linked with specific types of care tasks. Those providing a low-level of weekly caregiving were found to provide predominantly instrumental care tasks, such as babysitting and added household chores. In discussing their care-work, it becomes clear that the assistance they provide often resembles that of their non-caregiving counterparts:

> P1: Mostly I just keep him (sibling/care-receiver) entertained because he is very young and mom and dad have to take care of chores and cooking dinner. (Female, age 18)
>
> P2: Apart from the translation (parent did not speak English), I also help around the house because I am the oldest daughter, so I help my mom with cooking and cleaning. (Female, age 17)

For participants providing high levels of care, the general pattern found was for the provision of both instrumental care tasks as well as more age-atypical, personal care tasks. Of the latter types of care, participants were found to assist with the administration of medications to bathing and other hygiene care to the “child-proofing” of their homes. Participants with diabetic care-receivers all cite the need for late night kitchen runs, sometimes at three or four in the morning to assist with “sugar lows” and youth caring for persons with mobility issues reveal the often physically intensive and injurious nature of their care-work:

> We don’t have a ramp at the house so the physical work, like bringing my mom down the stairs (double leg amputee), has led to a back problem and my knees are hurting me. (Female, age 15)

Three young carers were providing such heavy lifting as part of their routine caregiving duties. Two female young carers provide heavy lifting up and down stairs for their double amputee parents while another male young carer provides frequent lifting of an alcoholic parent who requires assistance safely moving around the house during periods of insobriety. With over three decades of research establishing the high rates of injury caused from lifting among adult employees, especially nurses and long-term care workers (Akeyampong & Uscacas, 1998; Health Care Health and Safety Association, 2003; Nelson & Baptiste, 2006; Yassi, Gilbert & Cvitkovich, 2005), it becomes clear that youth are exposing themselves to potentially serious short and long-term physical injuries for which no health and safety workplace mechanisms exist to support them.

Taken together, the experiences of young carers in this sample were shown to exist in roughly two predominant categories. There are those who provide instrumental and occasional care for a family member (often a sibling) where the parent is the primary caregiver and there are those who provide highly personal, extensive and ongoing care for a parent and/or sibling(s) in the absence of other available adults. While the former may pose limited, if any, short or long-term risk to the youth's health and well-being, the same cannot be said of the latter.

5.5 RECOGNITION VERSUS REJECTION

Another recurring theme involves young carers' simultaneous desire for public recognition of their care contributions alongside a personal rejection of their carer status through secrecy and denial. Young carers both praise the efforts of understanding adults and peers with whom they confide in or seek assistance from, yet at other times take great pains to hide their caregiving roles.

This dualistic pattern of behaviour coincides with the second dimension of Daly and Lewis' (2000) framework that reveals how the historical provision of care, provided within a normative framework of obligation and love, works against its recognition as labour (p.285). More than just the provision of unpaid personal services, informal family care is a highly gendered and ethical practice representing a particular type of social relations characterized by personal ties of obligation, commitment, trust and loyalty (Daly & Lewis, 2000). Its historical association with the private sphere additionally perpetuates its enduring representation as extra-commercium (outside of the cold commercial world) – something of "a haven in a heartless world" (Lasch, 1976). Despite this leading to a broader lack of recognition among all caregivers that their care work is indeed *work*, youth face a double disadvantage due to their legal "minor" status and the normative incompatibility of their care work with their developmental stage.

5.5.1 Recognition

The importance of recognition and acceptance is most obvious when asking participants how their involvement with their respective young carer program benefits them. Youth uniformly note a positive impact derived primarily from public recognition of their carer status. Participants praise the program largely “because it recognizes you”. Not being accepted or recognized for their substantial familial contributions presents significant challenges for young carers.

Young carers also ascribe importance to being around other caregiving youth who are able to provide a unique form of social support through their shared experience:

> Getting to go to a place where people are going through something similar so they sort of know what it feels like and it’s a place where you can talk about it and get rid of some of your stress since you can’t really talk about it with your friends at school. (Female, age 15)

This sense of a joint shared identity is similarly noted as important in the international literature. In focus group research with Australian young carers aged 11 to 25 years, the discovery of the ‘young carer’ label was an empowering revelation that conferred value on their care contributions (Cass, Blaxland, & Cass, 2011).

During the interviews, it also became clear that not all recognition is received equally. Noting the often emotionally-charged nature of their home-based caregiving situations, participants reveal an appreciation with being able to talk about their problems “while having fun at the same time”. The value of the young carers program was central to this point. Here, youth could receive communal respite and recognition compared to other educational (e.g., principals, guidance counsellors) or traditional counselling-based settings which often center out the particular young person and their specific family situation. Instead, by providing youth the option of when to share their feelings and when to simply engage in therapeutic group-based programming, the young carer programs offer youth added choice as to how they wish to receive their recognition: individually or collectively.

Unfortunately for the young carers interviewed in this study, the lack of free time available in the evenings limits their attendance at young carer support groups. Attendant survey results reveal that young carers accessed these and other available supports an average of 4.6 times over the past six months. Additionally, only two of the fifteen participants remained in contact outside of their respective young carers program, with the remaining majority losing access to this peer network in between program attendance. While the types of programming and supports offered by such young carer programs will be expanded in Chapter Six, some of these include group outings (e.g. sports events, movie nights, summer camps), specialized information-based workshops such as stress management and cooking classes, and age appropriate information about their family member's condition.

5.5.2 Rejection

Despite appreciating social support, youth are also prone to hiding and/or rejecting their caregiving identity at times and for various reasons. Downplaying their caregiver status to both their peers, other non-relative adults, and even themselves is another polarizing theme evident within the accounts from young carers:

> P1: It just feels normal…he's my brother I take care of him...so that's what anyone would do right? (Female, age 18)

Others express the desire to avoid judgment from others, often in the form of pitying remarks from peers, teachers or strangers. Research into children with parental mental illness or disability reveals similar findings (Romano, 1976; Rose & Cohen, 2010). In fact, the second most frequently occurring response for why young carers programs are of benefit to them involves their being surrounded by people who "don't look at you with pity", which was a sentiment many problematized when referring to non-relation adults and peers who were aware of their situation. The desire to avoid judgment from others, who young carers feel do not understand the nature of their care-receivers' illness or disability, is at the forefront of their minds:

> P1: So, when my brother was first diagnosed (with austism), I actually didn't tell any of my friends cuz I was very scared they were going to judge me or my little brother…and I didn't want them to pity me or I would hear the 'oh that must be so hard' which I do get from some people when I tell them my brother has Autism. (Female, age 18)
>
> P2: People think … like … the fact that my dad is kinda sick and I have to care for him…they feel bad for me or pity me but they shouldn't cuz it's a part of my life and I'll get used to it. (Female, age 17)

Being under the age of 18 years presents additional challenges for young carers. As dependants or "minors", young carers worry about being sanctioned by welfare authorities. Specifically, the fear that revealing their care labour will lead to removal from the family home promotes a practice of self-silencing. One young carer reveals how she protects her family from withholding the circumstances of her care situation to her school-appointed counsellor: "My therapist doesn't even know about my home situation…I just lie to her and tell her everything is good".

Another instance of self-silencing emerges from inappropriate behaviours exhibited by the care-receiver. One young female carer illustrates this by discussing a particularly difficult developmental period for her autistic brother that involved his frequent hitting of anyone in his presence.

> I actually have trust issues…I had trouble confiding with the therapist because I didn't want her to see my brother's hitting as abuse…since when some people hear a relative is hitting me they immediately assume abuse and try to intervene. (Female, age 18)

Despite her proactively seeking the assistance of a counsellor to manage the strain of this particular situation, fears of outside intervention prevented her from fully opening up and accepting such support.

The fact young carers are prone to keeping their caring roles hidden is a consistent finding across the research in the United Kingdom (Earley, Cushway & Cassidy, 2007; Social Exclusion Task Force, 2008), Australia (Cass et al., 2009; Moore & McArthur, 2007) and the United States (National Alliance for Caregiving/United Hospital Fund, 2005). In 2008, an estimated 5% of U.K. young carers were admitted to state care because of parental illness or disability (Barry, 2011, p. 525). Fearing family disruption, families with young carers understandably opt to keep their situations hidden from authorities.

At other times, youth hide their caregiving due to bullying they experience from other peers, especially online via social networking sites. As revealed by participants, bullying results from instances where youth share private details of their home situations with peers and that trust is betrayed, motivating subsequent instances of bullying either from that peer or others. These events serve as a powerful deterrent against youth sharing their caregiving experiences.

Due to young carers' increased school absences and lateness record, interactions with teachers and other administrative staff are a frequent occurrence. Some young carers deliberately decide to withhold information about their caregiving from educators. While two students cite meaningful interactions with educators, the majority reveal they are met with insensitivity, disbelief, or apathy. This finding is corroborated in global research on young carers (Barry, 2011; Bolas, Wersch, & Flynn, 2007; Eley, 2004). Teachers and other adults sometimes reject, dismiss or minimize the impact of young carers' work:

> I couldn't finish homework a couple of times because things were going on with my brother and he (teacher) would make comments like 'oh it's a valid excuse for your major stuff but not for your minor stuff'. (Female, age 18)

Educators and administrators require training so that they may more effectively help young carers manage their educational and caregiver loads as well as refer them to additional support services when necessary. Teachers’ negative attitudes have been shown to compromise young carers’ attainment of good grades and future educational opportunities (Barry, 2011).

5.6 BENEFIT VERSUS PENALTY

Young carers derive a range of positive benefits from their caregiving, including added maturity and empathy as well as the strengthening of familial bonds. Notwithstanding these gains, young carers incur a wide range of negative consequences that affect their present and future social, emotional and educational development. Together, these negative consequences produce a powerful penalty referred to in this study as the ‘young carer penalty’.

5.6.1 Positive consequence of caregiving

Global research documents various benefits derived from the caregiving that youth provide. Notwithstanding any social desirability bias that may lead participants to over-report positive emotions in lieu of negative ones, youth’s reflections on their caring roles are largely positive.

Young carers in this study collectively recognize and acknowledge the positive aspects of their caregiving and the important roles they play in their families. The pride they take from acknowledging the important contributions they make is evident. Moreover, none of the participants express a desire to halt their caregiving altogether. As summarized well by one such young carer: “I don’t know what a teenage life is like … but I wouldn’t want to change anything”.

As young carer researchers demonstrate (Charles, Stainton & Marshall, 2012; Moore, 2005a,b,c; Carers Australia, 2002; Pakenham & Bursnall, 2006), early caregiving provides an opportunity to build closeness, instill feelings of pride and competence and foster empathy and compassion. Participants in this study were also shown to derive such benefits from their caregiving.

> P1: My caregiving is fairly rewarding, I definitely think that because of my brother I have learned a lot more about empathy and helping people who have difficulties. (Female, age 18)

Some young carers also discuss changes to life priorities and personal goals as a result of their caregiving. A desire to pursue care-based careers was noted by more than one participant. One participant reveals how her application to a social work program was motivated by her desire "to help people like my brother". For another, the desire to become a doctor was inspired by her mother's health issues that introduced her to "all types of different careers in the hospital". These youth are cognizant that their caregiving labour provides them with early expertise to enter care-based professions, the knowledge of which motivates their future career aspirations.

5.6.2 Negative consequences of caregiving: The Young Carer Penalty

In spite of probing both positive and negative consequences of youth's caregiving, the majority of accounts were of the negative variety, a finding similarly reported by Aldridge and Becker (1996) when reflecting on their research foray into U.K. young carers. As a result, this section presents the evidence for the unique 'young carer penalty', a term coined to build upon Nancy Folbre's (2012) conceptualization of the gendered 'care penalty' experienced by adult women (especially mothers) when performing care work.

The young carer penalty experienced by participants exists across a range of professional (i.e. educational and employment-based) and personal (emotional, familial and social) domains. The magnitude of the young carer penalty is also shown to link up to the level (or intensity) and types of care provided, with those sample participants providing greater levels of weekly care, in addition to more personal and physically intensive care tasks, experiencing the greatest penalty.

5.6.2.1 Professional Penalties: Employment and Education

Young carers experience a range of penalties that negatively affect their short and long-term educational and employment opportunities. First, irrespective of the level of caregiving they provide, very few young carers are able to take on paid employment due to their added responsibilities at home and the ‘on-call’ nature of their caregiving. In this sample, only two young carers were engaged in casual, part-time employment for an average of five hours per week at local, independently-owned businesses (a salon and a café). These particular positions were sought out because of their flexibility and familiarity with the youth’s unique family needs. When probed whether any of the youth considered working for larger youth-friendly companies, such as McDonalds[28], it was clear that they recognize the added difficulty in negotiating flexibility with large companies. One of the more senior participants in the sample reveals her difficulty in trying to gain employment with one such inflexible workplace:

> Recently there was a job opportunity for a drug store worker and they wanted me to work nights and it was far away but I realized if I took those night shifts they (her parents) wouldn’t be able to cook dinner and would have to rely on ordering in so I had to turn the job down. If I found something that involved less hours maybe I would have taken it. (Female, age 18)

Education is also negatively impacted by excessive caregiving. Lack of sleep, concentration difficulties, increased lateness, absences and a lack of available time required for homework and studying are just some of the penalties that young carers experience. Youth cite

---

[28] McDonald’s is one of Canada’s largest employers of youth: with roughly 65% of its staff between the ages of 15 and 24 years old (Mcdonalds.ca).

their daily struggle between satisfying their caregiving and educational demands which in turn leads to their feeling simultaneously overwhelmed and exhausted. Several participants wish there could be "more hours in the day". Quite often, the juggling act of managing both educational and caregiving demands results in a sleep deficit that spills over into the classroom:

> P1: I might be distracted or fall asleep in class or I'll show up late because I had trouble sleeping or things came up. (Female, age 15)
>
> P2: I am so overtired that I can't fall asleep when I want to but I fall asleep during the day. (Female, age 15)

Direct losses in the form of increased school absences also occur. Accompanying survey data results reveal an average of 6.5 days of school missed over the preceding three months due to caregiving-related events. The large standard deviation of 10.5 hours (min=00hrs, max=30hrs) reveals the tendency of young carers who provide low level caregiving to miss few or no days juxtaposed with those youth providing high level of care who miss upwards of a full month over the preceding three months. Often, appointments, surgeries or other health-related emergencies involving the youth's care-receiver prompts such longer-term absences. One such example of this involved a female young carer whose diabetic mother's unexpected heart attack led to a period of extended educational absence necessary to provide the supplementary home-care needed to assist with her mother's recovery.

To contextualize these educational absences, the Toronto District School Board calculates an 'absenteeism rate' by dividing the number of days a student is absent by the number of days that student is registered in school (TDSB, 2009). The current 2015-2016 absenteeism rate for TDSB students in Grades 9 to 12 is 9% – a value that the TDSB has deemed problematic and targeted a 50% reduction for the 2016-2017 calender year (TDSB, 2016). Using this same formula for this study's sample participants reveals a caregiving-specific absenteeism rate of 10.8%[29]. This figure does not account for any additional non-caregiving related absences related to personal illness or injury. In hindsight, the accompanying survey could have included a global "total days of school missed" question with a sub-question probing the total days missed resulting due to caregiving-related issues. In future surveys, this can help address the proportion of absenteeism penalty accounted for by caregiving related absences.

As one extreme case of the absenteeism penalty, one young carer whose single parent battles substance use and mental health issues missed one full year of school due to an oversight in the registration process from junior school to high school, the developmental effects of which were noted during the informed consent process. Specifically, consent forms were reviewed with the group prior to discussion commencing, with participants provided the opportunity to have any questions about the research, risks or benefits of their involvement clarified before commencing discussion. This particular young carer was taken into a separate room by the young carer program staffer on site, returning to join the group about 25 minutes later (during which I engaged the remaining participants in light conversation until all participants were seated). After the focus group ended, a debriefing with the staffer on site revealed that the separation of that youth was due to the reading and comprehension level of the participant. The staffer's removal of the participant in order to provide a one-to-one review of the consent form was dual-intentioned to avoid holding up the group while averting the participant from signing the form without fully understanding it (due to the potential embarrassment the participant may have experienced from asking additional help or clarification questions).

---

[29] This figure was calculated by dividing the mean days absent value (6.5) by the number of days students spent in school over the preceding three months, assuming a five-day school week (20x3=60 days).

For those times when young carers are unable to complete educational assessments on time, sporadic public outbursts of anger or tears result. Having a "meltdown at school" occurred on several occasions among young carers in this sample. One participant recounts an incident with a guidance counsellor where her inability to complete yet another homework assignment left her so inconsolable that her parents had to be called to pick her up from the school. A male young carer in the group notes his tendency towards more aggressive outbursts of anger where he throws or flips his paper off his desk during class and then will "just get up and go straight to the principal's office because I know I will have to go there anyway". Despite having only one male young carer in the sample who was providing high level caregiving, the nature of his outbursts conform to gender-normative scripts. Specifically, compared to female participants in the sample, whose meltdowns involve crying and confiding to their friends or teachers, the male participant resorts to more aggressive, bordering violent outbursts. These gendered norms of acceptable behaviour provoke added negative consequences for male young carers who are more likely to be branded a "problem" by teachers and other professionals. Indeed, this male young carer notes increased detentions and even a suspension related to such outbursts.

Taking part in extracurricular activities, including the 30-hour minimum volunteer quota required to satisfy provincial graduation guidelines, is also a difficult task due to the restrictions on young carers' time outside of school. Many note they are unable to join extracurricular activities or school groups due to the afterschool meet times which often conflict with their caregiving.

The net effect for many young carers is a diminished educational performance. Three participants cite having failed at least one course and another two required summer school to bring up their low grades. This reality is particularly distressing for the more senior young carers whose grades and lack of extracurricular record affects their postsecondary applications. Three of the five senior young carers aged 17 and 18 made special mention of the need to "make up" for their lack of educational resumes by taking extra night-school or online courses to bring up their grades. Some were making frenzied final year attempts to join multiple extracurricular groups. As one young carer reveals, the result is an even more harried final year of secondary school that often keeps her up at night thinking about "all the things I need to do and I'm just like 'oh my god I can't sleep' and there's a tear rolling down my eye" (nervous laughter).

For more than one participant, the decision is made to postpone postsecondary education until their caregiving subsides. As revealed by one such participant:

> I doubt I can leave them and I don't want anything bad to happen to them so I am thinking about holding back on college and university until they are better … even if I have to wait until I'm 40 I will … but I won't go until they are better. (Female, age 17)

This more explicit acknowledgment from more senior young carers of their care-based educational penalty is consistent with Australian research comparing the accounts of younger carers (aged 7 to 17) and young adult carers (aged 18 to 25). In Hamilton and Adamson's 2013 study, young(er) carers under the age of 18 had a much stronger sense of possibility about the future (despite sharing similar future constraints) than those 18 years or older whose lengthier care trajectories facilitated more realistic adjustments to their future aspirations (Hamilton & Adamson, 2013, p. 113). It is very possible that younger carers (aged 15) in this sample, who are interviewed at the beginning of their high school trajectories, fail to recognize the accruing educational disadvantage conferred by their caregiving until the final-year postsecondary application process makes that disadvantage clear.

For the sole senior young carer in the sample who has concrete plans to attend post-secondary education, guilt and attachment issues exist. Upon accepting an offer to attend university for the following year, she reveals how her plans to move into residence are marred by concerns of her exit from the family home. With urging from her parents to live on residence, she decides on a local university with a short commute time of under 45 minutes. Even still, her concern that the university is “quite a distance away” is at the forefront of her mind, ushering in concerns for how the care she provides will be recouped in her absence:

> I also feel stressed I won’t be at home to help my parents five days of the week with dinner and my brother so I feel guilty … and what if mom goes on a trip then dad will be completely on his own … so I have worry, nervousness and guilt … but I do plan on coming home on the weekends. (Female, age 18)

Global young carer research substantiates these findings, noting that while caring responsibilities do not appear to affect youth’s *ambitions* to go to university, they do affect other postsecondary decisions. In particular, the choice of institution, especially the proximity of the university to their home, the courses studied and the hours per week that youth are able to attend school are shown to be impacted by youth’s caregiving (Hamilton & Adamson, 2013).

5.6.2.2 Personal Penalties: Familial, Social and Emotional

Familial bonds are often strained by excessive caregiving demands. Episodic in-fighting and feelings of resentment are evidence of *familial strain* found within this sample of young carers. Causes of familial strain are largely explained by the nature of the illness and/or the perceived failure of other family members to contribute care. For one participant, the nature of the care-receivers’ illness and the accompanying role reversal provokes feelings of anger and frustration:

> I hate my mom somewhat but I don’t in a way because she is my mom and she gave birth to me … but I’m frustrated because she is an alcoholic so sometimes it feels like I am a parent but a parent of a 5-year old child who is a full grown person. (Male, age 17)

A perceived unequal division of caregiving among family members causes additional tensions within the family unit. Some participants reveal how relationships become strained and at times lead to emotional responses or outbursts between family members:

> P1: Since my brother has been sick my dad has been really not helpful and that has worsened the situation … so things have changed between us. (Female, age 15)
>
> P2: My younger sister thinks she can do the bare minimum and that causes a lot of arguments … so like my dad just got really angry and so did my sister … so there is a lot of yelling … and then crying … and then more yelling … and more crying … and I'm pretty sure my next door neighbours hear a lot of stuff they shouldn't hear. (Female, age 15)

Familial strain is also aggravated by a young carer's lack of "alone time", a rare commodity in their households. If secured, alone time often comes with an explicit or implicit guilt price-tag. As one young carer reveals: "My family will get mad at me if I want to spend more time alone because they think I'm not being helpful". Numerous youth echo this sentiment, revealing how parental resistance to young carers' requests for non-caregiving time, both within and outside of the household, can incite a mix of sadness, disappointment, or outright rejection. Often, the tendency of parents to "pull out the caring card" in order to draw the young carer back into caregiving is justified as a way to balance parental paid work obligations. Other times, parental requests for their children's assistance with caregiving is motivated by familial love and the parents' desire to spend added time with the young carer (and not solely the care-receiver). In any case, whether the young carer is met with overt resistance when requesting and/or securing alone time or whether that resistance is internalized by the youth privately (i.e., through their own feelings of self-guilt), it is clear that their personal need for space or alone time is secondary to the needs of their family.

A second negative consequence for young carers involves the *social handicap* that results from their limited opportunities for respite and peer group socialization. The majority of youth indicate they have very little "free time" to pursue hobbies or leisure activities, less still to spend with friends. When asked directly if their caregiving impacts their social lives, they all replied in unison, "WHAT SOCIAL LIFE!" Given the added social isolation of young carers, many note an increased reliance on web-based socialization tools that can be accessed at home in between caregiving duties. Seeking out small windows of time throughout the evening (e.g., five minutes) to log onto Facebook or call a friend in between cooking, cleaning and helping out their parents is a common theme expressed by young carers. Even when young carers are able to secure rare leisure time outside of their households, it is less than their non-caregiving counterparts, a fact they are quick to point out:

> P1: …on the rare occasion I get to go out with them (her friends) … I mean once every 4 months. (Female, age 17)
>
> P2: My parents let me go out but it's not as often as a normal teenager … maybe once a month. (Female, age 17)

Young carers' increased isolation from peer networks is exacerbated by the restriction of their leisure time to the household, including reading, computer use, painting, cooking/baking, and listening to music. As an example, one girl cites 'music' as her hobby, discussing how she sings along with her favourite music when she is cooking and cleaning, noting that "if there was no music, I wouldn't be here today … it really calms me". When probed if her love of music extends outside of the household, that is, whether she attends concerts or other related shows, the answer was no. Despite young carers finding ways to negotiate opportunities for home-based respite in between their caregiving duties, the fact that their care work is located within their households makes it all the more vulnerable to encroachment.

The lack of available free time is validated by young carers' heightened feelings of "missing out". Such feelings are most likely to occur when amongst their peers at school when learning of missed parties or social events. The limited free time young carers possess can create strain among existing friendships as revealed by one participant: "I've had a best friend for 11 years but I haven't seen her in three months and we've been fighting cuz I haven't had time to see her".

Given this heightened sense of missing out, it is understandable that some young carers attempt to make up for lost socialization time outside of school hours *within* school hours. More than one participant notes how this often lands them in trouble with their teachers:

> … the teacher had to glue my desk to hers because I couldn't pay attention in class … I think part of this may be because I don't get to see my friends a lot outside of school so when I am there I try to talk to them as much as I can. (Female, age 15)

When participants were asked whether they try to make up for lost socialization time outside of the household by inviting peers over to their family home, extenuating circumstances were shown to stand in the way. Several discuss their refusal to invite peers to their households for fear or embarrassment, especially in families dealing with a terminal illness and/or substance use problems. One young carer reveals her tendency to avoid extending such invitations due to the frequent sickness caused by her mother's terminal cancer. Her admission that she is sometimes embarrassed "cuz the house really smells…and I don't want people's first impressions to be of my mom sick on the bed", an understandable response to this particular situation. Another participant reveals how his mother's condition prevents him from inviting peers to the household:

> I NEVER bring people to my house ... there's no way I will bring people over. So, if people ask to sleepover I just say no and change the subject … my mom can be verbally abusive when she drinks ... and she threatens people sometimes when she is drinking and she won't remember it when she is sober. (Male, age 17)

Additional evidence of the social handicap young carers incur results from the mismatch in current life-course trajectories between young carers and their non-caregiving peers. Many participants note they "do not feel like teenagers" which reflects the concept of role reversal first outlined in the parentification literature. Specifically, among young carers' peer networks, evidence of parental-role spillover corroborates the caretaker syndrome discussed by Valleau, Raymond and Horton (1995). Several participants reflect upon the uneven nature of their friendships triggered by such parental role-spillover:

> P1: I'm usually the mom type of my friends … so they want to do all this friends stuff but I'm such a worrier I'm always like 'no guys we can't do this or that' ... so they call me Debbie downer cuz they just want to explore and act like teenagers and I'm always being responsible. (Female, age 17)
>
> P2: I'm like a parent now … although I know I'm too young to do that. … I tell my friends they shouldn't be doing certain things that may be bad for them and they get mad and sometimes they yell at me 'you're not my father!' (Male, age 17)

Paradoxically, some of those very same carers note a reliance on friends for pseudo-parental support which they see as lacking in their own families. In one case, a young carer says she fears adding to the existing burden experienced by her dual-care receiving parents:

> Since they are trying to get well ... they can't really be a parent like they signed up to be when I was born. … they try to help as much as they can but my friends have been more of a parent to me ever since they got sick. (Female, age 17)

Young people's caring roles thus produce a social handicap in two ways. First, the intensity of their caregiving demands works against their efforts at socializing with peers and/or engaging in intra- or extra-household related activities. Second, feeling out of sync with their peers, young carers experience what they describe as unbalanced friendships.

The final domain in which negative consequences are found to exist involves *youth's emotional health and well-being*. Young carers experience largely unresolved emotional distress. Many choose to suffer in silence and internalize their distress as their own fault. Often, the distress young carers experience stems from their elevated fears and concerns pertaining to their care-receiver's health and well-being. The stability of their families is a worry constantly weighing heavy on their minds. One young carer revealed how she once sought the advice of a lawyer to better understand what may transpire in the event something happened to her parents. Would her sibling be taken away? Would she become the primary caregiver of her care-receiving younger sibling? Worrying, a frequent occurrence in the day-to-day lives of young carers, seems to extend to everybody but themselves. As one young carer in the group succinctly summarizes: "I just worry about everybody but myself".

This concern for family members can cause sleep deprivation. Accounts of unanticipated emergency hospitalizations and other pressing care crises are shown to prevent young carers from sleeping. As one young carer reveals, his mother's drinking is the reason that often keeps him up at night:

> Normally I can't sleep because if my mom's been drinking. … I worry about if she fell and maybe broke her leg and how long will she be there until I wake up and help her … so I tend to stay awake until she falls asleep … but sometimes she stays up all night so I'm up all night. (Male, age 17)

For many, the resulting stress of their caring role leads to heightened uneasiness and unrest. The majority of participants note they currently suffer from anxiety, evidenced by accounts of feeling “really irritable”, “anxious” or “on edge”. Sometimes such mundane events as “people standing in the hallway at school” or “people walking super slow” trigger young carers’ anger and/or anxiety. Numerous young carers cite the occurrence of panic attacks which, despite not being explicitly identified as such by the youth, were evident in the following accounts:

> P1: I get a feeling of butterflies in my stomach and sometimes I feel like I’m going to faint … or I freeze up. (Female, age 15)
>
> P2: … I’ve had chest pains … trouble breathing and felt like my chest was going to explode. (Male, age 18).

The added stress of caregiving is corroborated by a recent Statistics Canada report looking at Canadians aged 15 years and older. Among this age-aggregated caregiver cohort, 28% find providing care somewhat or very stressful and 19% indicate that their physical and emotional health has suffered in the last 12 months as a result (Sinha, 2012). These results are magnified with the intensity or level of care, that is, the number of hours of unpaid care provided in a given week (Sinha, 2012). A similar pattern holds for young carers in this sample, with those providing medium and high levels of care incurring the greatest penalties to their physical and emotional well-being.

5.7 APPROACH VERSUS AVOIDANT COPING

In the global research on adolescent coping, two general categorizations of coping styles have been supported: approach and avoidant (Packenham & Bursnall, 2006). Approach strategies involve direct efforts to alter a stressful situation and include acceptance, problem solving and the seeking out of supports while avoidant coping is characterized by the absence of attempts to alter the situation and includes avoidance, denial, distraction and wishful thinking (Connor-Smith et al., 2000; Dempsey, Stacy, Moley & Curr, 2000; Early, Cushway & Cassidy, 2007; Herman-Stabl, Stemmler, & Petersen, 1990).

Approach-style coping can be linked to the concept of resilience. Resilience refers to peoples' positive capacity to cope with significant adversity and includes "both the capacity of individuals to navigate their way to health-sustaining resources, including opportunities to experience feelings of well-being, and a condition of the individual's family, community and culture to provide these health resources and experiences in culturally meaningful ways" (Ungar, 2008, p.225). Research on young carers points to a range of approach-based coping strategies employed by young people to ameliorate the stressors of caregiving. These include the adoption of the young carer label and the supports that go with it (Cass et al., 2009), the proactive utilization of online aids, such as the internet, to locate and access beneficial self-help resources (Smyth, Blaxland & Cass, 2007) and the negotiation of accommodation plans with educators, specifically in terms of deadline extensions and alternative homework arrangements (Moore & McArthur, 2007).

Young carers have also been shown to engage in avoidance-based coping that can aggravate their existing stress. In a sample of young carers with parental MS, Pakenham & Bursnall (2006) show that compared to non-caregiving youth, young carers are generally less apt to utilizing problem solving and social support. Young carers have also been shown to isolate themselves from other children of the same age in addition to other family members (The Children's Society, 2011) and engage in self-harm, increased truancy, problematic sleeping, eating and substance use (Cree, 2003; London House of Commons, 2008; Salter, 1999). The lack of more effective coping has been attributed to their age, with young carers seen as not mature enough to have developed more constructive forms of coping (Docking, 2000). The reliance on avoidance-based coping by many young carers can also be attributed, in part, to the real or hypothesized stigma or intervention that can result when they seek out external supports (Cass et al., 2009; Moore & McArthur, 2007).

The results of this study indicate that young carers simultaneously employ approach and avoidant-style coping. This paradoxical pattern of coping validates research from a U.K. -based study where young carers experiencing high stress and high burden worked at tackling some of the problem while concomitantly avoiding other aspects of it (Early, Cushway & Cassidy, 2007).

5.7.1 Approach coping

At times, young carers demonstrate remarkable resilience in the ways that they cope with their added responsibility. Young carers cite a variety of constructive stress-relieving activities that include baking, television viewing, internet use, painting, prayer and exercise. Even when probed whether youth engage in any forms of illicit behaviours such as alcohol consumption or recreational drug use, the general consensus is summed up by one young carer who aptly notes: “I think if we did something unproductive it wouldn’t be good for the person we’re caring for”.

To help balance the lost opportunities for socialization outside of school hours, many young carers use lunch or spare periods at school to “catch up with friends”. Attending young carer programming is another strategy that participants note helps in counteracting their general isolation and reduced opportunities for socialization. For many, being involved with a young carers’ program is instrumental in widening their peer networks. As one female reveals: “I mostly come for friends because I don’t have any at my school”.

Approach based strategies are also used to help recoup some of the lost opportunities for school work at home. Some young carers note the use of lunchtime or spare periods at school as a key window with which to catch up on homework not completed the evening before. For those more senior participants in the second focus group, the offering of dedicated "homework-help nights" by their young carers program is a highly praised commodity. The availability of "a quiet space to do work" is critical for young carers who cite this feature as largely absent in their households.

For several other young carers, scaling back on sleep is the preferred method to completing homework and other educational demands, with participants citing the need to "stay up super late" at night after their care-receiver surrenders for the evening. Attendant survey results corroborate this finding, with 93% of sample participants responding 'yes' to the survey question *"When you need more time, do you tend to cut back on your sleep?".* While this technique surely helps them recoup some of the lost time to complete homework, it is not without its problems. First, the deleterious effects of sleep deprivation are well documented in a recent Canadian study highlighting the consequences of this "sleepidemic" among Canadian children and youth (ParticipACTION, 2016, p. 8). Here, chronic sleep loss in children and youth is shown to be tied to insufficient physical activity levels, increased sedentary behaviours, and higher rates of depression and suicidal thoughts. Second, indirect educational impacts are found to co-occur with sleep loss. Numerous young carers cite missing entire days of school and/or morning classes, in particular, because they are "too tired to get to school on time". If they do make it to school, it is not uncommon for many young carers to fall asleep in class and/or cite an increased difficulty with paying attention, a side effect they admit is often linked to added disciplinary action from educators.

While young carers in this sample take steps to tackle their competing demands head on, a general point of caution must be made about their presumed added resilience. As young carer research demonstrates, young carers' perceived resilience and self-sufficiency can be a limiting factor to the widening of their social networks, certainly in the way of those involving supportive adults (Barry, 2011; Phillips, 2010). Corroborating evidence of this is seen in this study when young carers express withholding their needs due to their own perceived self-capacities for coping:

> I could tell my teachers but they would make me see the school counsellor and I don't feel the need to talk to them … cuz I have my own ways of calming myself down, like I just go outside and walk. (Male, age 17)

Another caveat to revisit is the fact that this sample of participants represents a special cohort of young carers due to their family support (i.e., in registering them with the young carers program) and dedicated young carer program assistance. Arguably, these two components have helped to make this particular sample of young carers a more competent, better functioning group. It is possible that the young carers in this sample were engaging in more avoidant-style coping prior to their involvement with the young carers program, and that only through this involvement did they become equipped with the more constructive, approach-style of coping they are currently shown to employ.

5.7.2 Avoidant coping

Young carers simultaneously employ a range of avoidance-based, often externalizing strategies aimed at self-medicating and/or reducing the stress of their caregiving. Behavioural avoidance is accomplished by a variety of means. One young carer notes how sleeping helps her to "just forget everything" while another partakes in "stress baking" in lieu of sleeping. As revealed by this latter young carer, overnight emergency hospitalizations of her care-receiver prompt the following behaviours:

> So when my mom goes to the hospital sometimes … like for emergencies … I have this urge to bake and cook ... so at like 3 in the morning I will be cooking breakfast. … but I don't eat it so I just give it to random neighbours. (Female, age 15)

Externalizing behaviours are noted by many carers and involve problematic food and substance use. One female participant "chews vitamin C's" as a form of self-soothing and another confides to having "an eating disorder, depression and anxiety" for which she receives professional help. Two others cite the use of smoking as a way to relieve stress and nearly half indicate other forms of problematic food patterns ranging from undereating/loss of appetite and subsequent weight loss to overeating and subsequent weight gain. Attendant survey data results reveal additional behaviours not divulged during the group discussion. In one of the survey questions, young carers were granted the opportunity to write in any additional coping strategies used to handle difficult situations (Q.21, Appendix E). The responses are disheartening. Four respondents (27%) disclose self-harm in the form of cutting as well as suicidal ideation.

Recent research suggests the risk of substance abuse problems among teens is higher for those "self-medicating to cope with toxic environments, untreated trauma, and underlying psychological conditions" (Canadian Centre on Substance Abuse, 2007, p.3). While youth's caregiving is not necessarily toxic, unless it is provided in a parentified manner whereby it coexists with parental neglect and potential abuse, there is evidence that the added stress incurred promotes problematic substance use. More than one participant resorts to over the counter cold medicine as a sleep aid (i.e., Nyquil) and another relies on caffeine aids (i.e., diet coke) to stay alert and complete her homework. For this latter participant, the consumption of diet coke creates concern from her parents: “They had to speak to me about my diet coke because sometimes they will leave me and when they come home I have finished a case of diet coke cuz I’m stressed”.

Interestingly, the mismatch between the survey and focus group data reveals that many young carers are not consciously aware they are self-medicating. Specifically, those who recounted the use of sleep and caffeine aids during focus group discussion failed to indicate so on the survey questions probing for such coping mechanisms. This also reveals a limitation, more broadly, of relying on survey research in the area of risky behaviour more generally but of risky behaviours among children and youth in particular. The use of a qualitative focus group design proved most useful to uncovering such behaviours due to participants’ ability to build off one another’s responses and unearth such coping commonalities. Moreover, such findings may not have been revealed in a one-to-one interview design that failed to explicitly probe for such behaviours. The withholding of self-harm and suicidal ideation from the group discussion reveals that despite focus groups shown to be beneficial in easing comfort levels among youth in some areas of discussion, there still exist areas deemed too personal to share in a group format.

5.8 CHAPTER CONCLUSION

Using qualitative (i.e., focus group and individual interview) data from a sample of 15 young carers from the Niagara Region and Greater Toronto Area of Southern Ontario, this research provided a first-hand account of the complex and often contradictory nature of youth-based caregiving. Drawing on theories grounded in feminist political economy and child psychology, youth-based caregiving was shown to be a be a varied and often contradictory set of activities that constitutes a form of hidden labour carrying with it a range of benefits and penalties.

First, the degree of care undertaken by young carers in this study (i.e., the unpaid hours of caregiving per week and the types of care tasks) was shown to exist in two crude categories. On the whole, there was a clear contrast between those low-level caregivers providing both occasional, instrumental care for a family member (often a sibling) where the parent was the primary caregiver and those who provided highly personal, extensive and ongoing (high-level) care for a parent and/or sibling(s) in the absence of other available adults. Gender-based forces were also shown to impact the youth's degree of care, with female youth providing a greater level of weekly care even when other young males were available in the household. The only instance where conflicting evidence existed was in those situations in which the young person was an only child and there were no other available females left in the household.

Second, young carers displayed a simultaneous desire for public recognition of their care contributions alongside a personal rejection of their carer status through secrecy and denial. Highlighting another dualistic pattern, young carers were shown to value supportive adults and peers who were aware of their situations and could help them manage their additional burden or simply listen. Other times, they made efforts to hide or deny their caring roles, often out of fear of intervention, judgement or even bullying.

Third, and irrespective of the degree of care provided, participants identified positive benefits from their caring roles, including enhanced closeness with their care-receiver and/or other family members, added empathy, maturity, and compassion. In more than one instance, the caring role inspired future career aspirations that were tied to caring professions geared to helping others in similar situation as their care-receivers. Positive outcomes aside, the preponderance of those uncovered in this study were of the negative variety, a finding similarly reported by Aldridge and Becker (1996) when reflecting on their research into U.K. young carers.

With that said, the 'young carer penalty' is the term coined by this study to highlight the joint professional and personal penalties documented to exist among this sample of young carers.

Professionally, young carers providing both medium and high levels of care were shown to be held back from pursuing employment and educational-related opportunities. The variable and often on-call nature of their caregiving meant that most participants could not take on paid work, however limited. Building academic resumes was similarly a struggle, with the majority of young carers citing an inability to partake in co- or extracurricular activities, let alone keep up with their day-to-day homework, test and assignment deadlines. Effectively managing their student role demands was a challenge, due in large part to their higher than average care-related absenteeism rate and the added difficulty of staying focused in class resulting from both their sleep deprivation and their worrying for their care-receiver(s). Missing tests and assignment deadlines was thus a frequent theme among many. Together, this amounted to a diminished educational performance for several young carers that was felt most ardently by those approaching the end of their secondary school careers.

Professional penalties aside, youth incurred a variety of personal penalties that affected their familial, social and emotional well-being. Many youths reveal strained familial bonds, often linked to a real or perceived inequality in the provision of care, in addition to the limited opportunities for socialization outside of the household which result in heightened feelings of missing out. Indeed, friendships were tested by young carers' inability to partake in social outings outside of school time and once spoiled, resulted in subsequent bullying for more than one participant.

The fourth dualistic pattern to emerge relates to how youth manage the added stress and responsibility that result from their caring roles. Here, they were shown to simultaneously utilize both approach and avoidant-style coping. At times, young carers displayed impressive resilience in coping with their added burden by tackling their problems head on and finding constructive ways to reduce their stress. Other times, the utilization of avoidance-style coping via denial and externalizing symptomology aggravated negative aspects of their caregiving. Add to this the failure of many participants to recognize the potentially problematic and addiction-forming nature of certain avoidant-style coping mechanisms, and it becomes clear that the young carer penalty poses long-term carrying potential.

Despite the challenges of their caregiving, young carers were not interested in evading their caregiving responsibilities. Their deep commitment to their families and their tendency to deny their personal needs for the needs of their loved ones was evident in their personal accounts. Factoring in the added age-related challenges young carers face in managing their extra burden underscores the importance of formally supporting children and youth in their caring roles.

CHAPTER SIX[30]

Supporting Youth Caregivers: A Qualitative Review of Young Carer Services in Canada.

6.1 INTRODUCTION

Nowhere in federal, provincial, or municipal policy or legislation has the role of child and youth caregivers been officially recognized. The role of adult caregivers, however, has been well noted and linked predominantly to the increasing importance of community care in Canada's long-term care strategy. Whether prompted by the progressive de-institutionalization of aspects of health care, a rapidly aging population, or a desire on the part of older persons and persons with disabilities to age in place (British Columbia Law Institute, 2010), the rise of unpaid care among adults is well documented. These same factors encourage the growth of caregiving among children and youth. This chapter will focus on how the lack of progress made in developing young carer supports across Canada results from broader neoliberal-inspired restructuring to both the public healthcare sector but also the non-profit and community care sector.

It is no secret that a rising burden of care has been placed on Canadian families over the past two decades. In fact, a 2003 environmental scan of all those publicly-funded respite programs at the federal, provincial and territorial level was commissioned by Health Canada in order to provide information that may help "relieve caregiver stress and burnout in order to allow caregivers to attend to other areas of their lives" (Dunbrack, 2003, p. 2). In the definitions section of the report, however, the following is provided in relation to who *family caregivers* are:

---

[30] This chapter is a re-worked and expanded version of the published article entitled: Supporting young carers: a qualitative review of young carer services in Canada (Stamatopoulos, 2016).

> Most family caregivers are elderly spouses, middle-aged children of the elderly, parents of children and youth who are severely ill, disabled or developmentally delayed (Dunbrack, 2003, p. 4).

With Chapter Three's revelation that Canadian youth aged 15 to 24 comprised the third largest caregiver cohort in 2012, overtaking care provided by all those persons aged 65 years and older (Table 4.3), it becomes clear that youth's continued omission from existing definitions and policies surrounding care is problematic. Moreover, growing warnings from nonprofit and community service providers of the mounting contingent of child and youth caregivers in need of their services echo this oversight (Baago, 2005; MacSween & Maule, 2012; Waugh, Szafran, Duerksen, Torti, Grant & Shankar, 2015).

From a policy perspective, various factors work to inhibit the development of policies and supports geared towards Canadian young carers. First, the current mandate of Canadian health and social services is to "provide support either for the care recipient solely, or for the care recipient/primary caregiver dyad, but not to other members of the family in a holistic sense" (Baago, 2005, p. 6). Underpinning this mandate, of course, are the series of changes beginning in the late 1970's (later identified as 'neoliberalism') whereby the federal government radically changed the system in place by reducing health care funding but also removing the conditions on how the provinces and territories could spend those funds (Gindin et al., 2005). Second, cuts to the areas of nursing and child care and the attendant shift from hospital to home care have resulted in the transfer of an increasing amount of health and human services from the public to the private sector which brings with it an associated increase in the amount of social support and caring required by (unpaid) family workers and volunteers (Armstrong, 2003; British Columbia Law Institute, 2010; Pupo & Duffy, 2012). Third and concomitantly, additional programs once publicly provided have become off-loaded onto the non-profit and community (voluntary) sector without any commensurate increases to their human or financial services (Scott 2003, p. ix). The neoliberal objective of reducing the role of the state to minimalist via the contracting out of once publically provided services, is often positioned as a cost-cutting measure. With roughly 80% of the non-profit service providing sector (NPSS) dependent upon funding from governmental revenue sources (Eakin, 2007), subsequent reductions to NPSS contracts have led many such providers to be characterized as part of the "precarious sector" (Baines, Cunningham, Campey & Shields, 2014). Indeed, by 2003, almost half of Canada's 161,000 non-profit and voluntary organizations reported problems obtaining funding to meet their existing operating demands (NSNVO Factsheet, 2006). Additional evidence of the ongoing financial squeeze felt by those in the voluntary sector is evident when interviewing staffers. In one study of NPSS providers in Toronto, virtually all staff cited the need to donate their unpaid time to meet the growing demand for their services (Baines, Cunningham, Campey & Shields, 2014). Fourth, and as revealed in the Chapter Three, the continued failure to enumerate the full range of children and youth in most national surveys perpetuates their invisibility as a cohort of carers.

Appreciating that the Canadian young carer movement is still under a period of initial establishment, this chapter aims to fill three specific gaps to the existing literature. First, it will review the origins and current state of the young carer movement in Canada before moving to a second review of those best (young carer) practices currently operating in the United Kingdom – the most advanced model of young carer social programming and policy provisioning. Third and last, it will draw on qualitative data with frontline staff at each of the existing Canadian young carer programs to review the range of services available to such youth while documenting the barriers to improving their individual scope and reach.

6.2 THE YOUNG CARER MOVEMENT IN CANADA

Similar to other developed nations with young carer movements, the origin of the Canadian movement can be traced to a small group of social service providers recognizing an unmet need among youth in vulnerable families. Specifically, during home visits with clients and their caregivers, staff with the Alzheimer Society of the Niagara Region (ASNR) began to identify upwards of 70 children and youth taking on caregiving roles for a parent, grandparent or other relative suffering from progressive dementia. Quickly becoming clear that many of these children struggled with stress and anxiety, or other emotional problems (Baago, 2005, p. 6), the ASNR branched out to form the Young Carers Initiative of Niagara (YCIN) in 2003. Consisting of 14 concerned community agencies in the Niagara Region of Southern Ontario, their mission was to promote awareness of these youth and to alert member agencies (representing a wide range of community services for children, youth and adults, covering diverse health conditions such as HIV/AIDS, multiple sclerosis, brain injury, dementia, and autism) on ways they may better detect and provide referrals services for young carers.

Despite momentum building to better identify young carers among these organizations, there is still very little targeted programming to assist them in their caregiving roles. Moreover, outside of this small group of non-profit service providers in Southern Ontario, the wider national approach to health and social services delivery still revolves around the illness or disorder without paying sufficient attention to the caregiving aspect of the children’s lives. Instead, it is only when the young person becomes viewed as “parentified” or deemed a “problem” (i.e., by becoming depressed, suffering from an eating disorder, skipping school, acting out, being aggressive or manifesting a variety of other anti-social behaviours) that mental health and/or other social service agencies are called in to provide assistance (Baago, 2005; Charles, Stainton & Marshall, 2008).

Currently, only three dedicated young carer programs exist across Canada and each operates under the umbrella of larger non-profit organizations. The first program developed as a special project of the aforementioned Alzheimer Society of the Niagara Region (ASNR) in 2003, the second under Hospice Toronto (a palliative care program) in 2007 to service young carers across the Greater Toronto Area (GTA) and the final in 2010 under the Cowichan Family Caregivers Support Society (CFCSS) which serves youth residing on Vancouver Island.

The longest running young carers program (formerly the YCIN but now called the Young Carers Initiative (YCI): Powerhouse Project) can be classified as the most comprehensive of the three, currently providing a mix of predominantly individualized but emerging whole-family programming. With a total of six paid staff covering the Niagara and Haldimand-Norfolk regions and approximately 20 volunteers, services are provided at no charge to the 700 youth registered with the program since its inception.

Hospice Toronto's Young Carers Program (YCP) credits its start to the initial communicative efforts of the Niagara YCI and a 2007 Local Health Integration Network (LHIN) Innovation Presentation. Here, the director of the Hospice Toronto program became connected with those spearheading the Niagara YCI, leading to a working relationship being launched between the two that resulted in the development of an urban model that was up and running by the end of that same year in Toronto. Similar to the impetus behind the Niagara-based YCI formation, Hospice Toronto employees were increasingly identifying youth taking on active and often age inappropriate caregiving duties where, in many cases, they were the only able-bodied family member available to assist a loved one (Hospice Toronto, n.d). With a total of three paid staff on hand and a handful of volunteers, services have been provided at no charge to approximately 500 young carers utilizing its services since 2007.

The final young carers program operates out of Vancouver Island under the auspices of the Cowichan Family Caregivers Support Society (CFCSS) – a registered not-for-profit organization dedicated to supporting Family Caregivers. Starting as a three-year project in January 2010 and similar to the other programs, the Cowichan Young Carers program was inspired by increasing staff encounters with youth in substantial caring roles. Currently, the program includes two paid staffers and a handful of youth and adult volunteers working to primarily create awareness for young carers in the Cowichan Valley and surrounding First Nations communities. Although the exact number of young carers served is not known, staffers approximate the number to be roughly 50 since 2010.

Revisiting Becker's (2007) typology on the global levels of young carer awareness and policy response, Canada's failure to move past its "preliminary" placement is the result of three elements. First, there is no mention in any official (governmental) or legal documentation regarding the role that children and youth play in supporting their families by undertaking caregiving roles, let alone the provision of designated legal rights akin to those found in the United Kingdom. This lack of awareness that youth may be both providers and receivers of care is also evident in the current federal supports available to Canadian caregivers, with existing state-based supports geared exclusively towards working adults in the form of tax credits (the Caregiver Credit) and the Compassionate Care Benefit (part of the Employment Insurance 'EI' Act) that provides limited paid work leave for eligible employees with a family member that is "gravely ill with a significant risk of death" (Government of Canada, n.d). Second, and related to this, is the lack of wider public consciousness on the issue, with slim to no focus on these youth in the public media and the term 'young carer' a virtual unknown. Third, compared to the roughly 30,000 youth receiving dedicated young carer supports across the United Kingdom, only three young carer projects exist in Canada, having served roughly 1,250 young carers in total since their individual launches. The resulting situation is one where Canadian young carers are largely ineligible for any federal support, receive little attention in the Canadian media (with the term ‘young carer’ a virtual unknown), and have recourse to limited support from a small number of non-profit organizations struggling to provide supports based on limited and precarious federal support.

If we approach the issue in terms of a current unmet need, the most recent census data for England and Wales documented 432,250 young carers aged 05-25 who provided some level of unpaid care in 2011 (ADASS, 2014) compared to over 1.25 million Canadian youth aged 15-24 providing such care in 2012 (Chapter Four). While the statistics are generally meant to serve as minimum values due to various issues surrounding underreporting and methodological limitations of the survey instruments employed, they nevertheless amount to roughly 1 in 14 youth receiving caregiver supports in England and Wales compared to 1 in 1000 receiving comparable supports in Canada.

6.3 THE YOUNG CARER MOVEMENT IN THE UNITED KINGDOM

The earliest literature on young carers can be traced to the United Kingdom, where the development of what is still considered the foundational body of research on youth-based caregiving emerged in the late 1980’s to early 1990’s (Aldridge & Becker, 1993; Brown, 1989; Bilsborrow, 1992; Frank, 1995; Meredith, 1991,1992). Over the past three decades, research, policy and social programing for young carers has grown to constitute the most advanced young carer movement in the world, in large part attributed to the work of early researchers who were “critical in raising awareness among U.K. policy and practitioner networks on the experiences and needs of young carers and their families” (Becker, 2007, p. 35). With that said, reviewing the national level of awareness and recognition of young carers in the United Kingdom, the breadth of dedicated young carer programming, and the legal supports available may help to clarify what separates an advanced model from all others. A caveat to note is that while these three elements can be discussed as separate entities for the purposes of clarification, in practice they are intertwined and together reflect a key underpinning concept of recognition.

First, advanced young carer movements involve widespread national awareness and recognition of young carers, both in the public as well as among professionals and policy makers. In the United Kingdom, an extensive research base exists and young carers (i.e., as a distinct social category) were "well and truly on the map of child welfare services" by the early 1990's (Newman, 2002, p. 614). The term young carer is also part of everyday vernacular, with a Google search for "U.K Young Carers" drawing over 4.8 million hits, over a dozen TV documentaries dedicated to the issue, and various celebrity endorsements ranging from Helen Mirren to Ortise Williams to Jaime Oliver.

Additionally, widely circulated public information exists across the United Kingdom, with a host of print and digital documentation detailing the rights currently available to young carers. For one, registered young carer projects are housed on the National Health Service (NHS) website, with an online directory of all young carer centers searchable by postal code to provide a greater ease of access. An online "carer self-assessment" tool is also available on the NHS website to help young persons to see what kinds of resources may be available for them and to understand their legal rights. Finally, information for two government-funded help phone lines is provided by the NHS, with 'Childline' offering youth under the age of 19 a free and confidential telephone helpline to speak to a counsellor about any issue they wish, in addition to the 'Carers Direct' line that provides advice and support with caregiver-specific issues.

Second, the breadth of nationally dispersed social service programming for young carers remains unmatched by any other country, with over 350 dedicated young carer projects servicing approximately 30,000 children and youth and employing hundreds of workers and volunteers (Joseph, Becker & Becker, 2009). Most programs run through the voluntary sector and are funded from statutory agencies, such as local regional health authorities. The supports offered vary but are typically child-centred and aim to both assist youth in managing their caregiving load while alleviating some of the negative consequences incurred from it. Among these targeted interventions are leisure and respite-based activities, such as group outings and summer camps (with a nationwide 'Young Carers Festival' organized by the Children's Society attracting over 1000 young carers, government and policy makers since 2000) to more help-based, assistive workshops designed to counter some of the educational and emotional difficulties faced by young carers, including one-to-one support, counselling, and assistance within schools. Moreover, strategies seeking to prevent youth's entrenchment in caregiving are on the rise, with 'Family Conferencing' being one such technique that engages relevant social service providers with a wide range of family members to ensure access to mainstream health and social services for both child and adult (Ofsted, 2013). By involving parents and the extended family, this particular strategy aims to change, rather than merely provide support for the young person's caregiving role.

Owing much to the success of these interventions is the 'Whole-Family Approach' taken to the assessment of all individuals with an illness or disability in the United Kingdom, a model designed to better identify potential young carers at the first point of contact with a care or service provider. Much of the push towards this approach has been credited to the powerful response of young carer scholars to those from the disability rights camp. In the early years of the young carer movement, disability rights scholars began arguing against the development of dedicated young carer services and supports (Keith & Morris, 1995; Newman, 2002; Olsen, 1996; Olsen & Parker, 1997; Wates, 2002). Researchers taking this position argued that if formal services offered to those with care needs were appropriate or sufficient, there would be no need for family members to provide inappropriate levels of care, with the call for services to be improved for the person requiring the care. Responding to this critique, early young carer advocates (Aldridge & Becker, 2003; Becker, Aldridge & Dearden, 1998; Frank, 2002; Frank & McLarnon, 2007) maintained the need to provide dedicated services to young carers, *in addition* to providing more comprehensive needs assessments of vulnerable families as a whole, so that both sets of needs (i.e., those of the young carer and the care receiver) may be properly addressed.

Incorporating a whole-family approach into federal policy has also meant an attendant expansion of multi-sectoral partnerships and collaborations with professionals across health, social care and educational networks. Consequently, registered charities (most notably The Children's Society, The Princess Royal Trust for Carers, and Carers Trust) have taken a lead role in partnering with policy makers, nurses, school officials and public health staff to identify and assist young carers across the various health and social services. Successful collaborative efforts under these partnerships include: (1) the development of Young Carer ID cards that operate in some local authorities and alert adults, particularly teachers and social workers, about young carers' added responsibilities. This card also grants young carers the right to request deadline extensions and/or flexibility surrounding school absences without having to continually explain their personal situation in public, (2) the naming of a young carer 'School Lead' responsible for supporting young carers within their continuing professional development and, (3) the creation and dissemination of a wide range of educational and assessment toolkits, including Joseph, Becker and Becker's (2009) *Manual for Measures of Caring Activities and Outcomes for Children and Young People* to the development of ‘young carer channels’ on the existing *Makewaves* social media learning platform that operates in schools. Here, professionals with The Children’s Society have worked with *Makewaves* to provide a safe networking page for schools to use with young carers.

Undoubtedly the third, and arguably strongest, predictor of an advanced young carer movement is support from the national legislative body. In the case of the United Kingdom, legal rights were officially granted to young carers under the age of 18 with the 1995 *Carers (Recognition and Services) Act* that have since been strengthened with the amended (April 2015) Care Act. Now, more stringent protocols operate to better identify young carers, with the act stipulating that: (1) local authorities have the responsibility to assess a carer’s needs for support based on the *appearance* of need (new), and (2) young carers may be referred to available support services in their area or provide the option of “Direct payments” in lieu of services should the carer prefer to directly manage how their support is provided (National Health Service, 2015). What is noteworthy about this amended legislation is its incorporation of research demonstrating a weakness in its earlier form that placed the onus on the young carer themselves to request a needs assessment or be shown to undertake a regular and substantial amount of care. By expanding the scope of the legislation to provide an assessment based on just the *appearance* of need, a more preventative-style approach is enabled that additionally targets the many missed young carers and their families who may not have been aware of their rights or know how to ask for support.

6.4 FRAMEWORK FOR THE STUDY

Purcal, Hamilton, Thomson and Cass (2012) provide a framework for categorizing young carer support services according to three overarching goals: assisting young people who provide care (assistance); mitigating the caregiving responsibility (mitigation); and preventing the entrenchment of a young person’s caring role (prevention). While the framework was applied for those existing support services targeting Australian young carers, it may also be used to categorize supports in other countries while also clarifying service objectives and identifying gaps in service provision (Purcal et al., 2012).

Assistance-based (or assistive) services aim to support young carers by helping them cope with their added responsibilities and/or encouraging them to seek additional help, either for themselves or the person they care for. These services are usually provided on a short-term basis and include interventions such as: counselling for the young carer; information on other services or the provision of self-help strategies, and access to peer support groups (Purcal et al., 2012). Mitigation-based services work to reduce care responsibilities by either lowering the intensity of caring or by cutting down the time spent on caring, for example through respite services for young carers or tools to reduce the long-term negative educational or social impacts of caring on the young person. Interventions in this domain include education assistance, training and employment assistance and/or financial support (Purcal et al., 2012). Preventative strategies aim to avoid the entrenchment of a young person's caring role and the associated negative outcomes across a range of domains, including school, employment, health and well-being. These approaches provide support to the whole family when a disability or chronic illness first manifests itself and in the case of youth who have already taken on a caring role, help to create an optimum combination of formal and informal supports that are tailored to each individual family. As such, they are personalized, encompass a whole-of-family approach, and involve an integration of social, health and disability services (Purcal et al., 2012).

While the framework demarcates three distinct categories of young carer supports, there is operational overlap in practice. As Purcal et al. (2012) point out, many services aim to achieve more than one goal, with young carer camps designed to provide assistance in the form of access to peer support and information while simultaneously mitigating the strain of caregiving by providing respite.

6.5 FINDINGS: INTERVIEWS WITH YOUNG CARER PROGRAM STAFF

In-depth interviews were conducted by telephone with a purposive sample of frontline staff at each of the three existing Canadian young carer programs. Interviews lasted roughly 75 minutes and were conducted between January 12th and 23rd, 2015. Targeted for discussion were the origins of their respective young carers program, the range of services offered to registered users and the barriers standing in the way of program growth and/or expansion.

6.5.1. The Range of Young Carer Services in Canada

Currently, the range of dedicated young carer services in Canada remain either assistance or mitigation-based, with none operating at a preventative level.

The YCI: Powerhouse Project provides the largest range of weekly services to young carers in the Niagara, Haldimand and Norfolk regions, offering a mix of individualized and, albeit limited, whole-family programming. Assistance-based services range from home-visits or one-to-one counselling sessions (or referrals to other counselling services) to peer support group access for both teenagers and young adults. Life skills programming is another integral component of the program, with workshops aimed at developing a range of self-help tools among young carers, from “Calmcare” where youth learn to use bubbles as a fun way to practice deep breathing techniques to “Fit for Youth” where physical activity is used as a form of decompression therapy. Other workshops have been added to the roster over time as an unmet need is discovered, with one such example being the development of youth-based cooking classes triggered by a situation where a young carer’s parent was taken away in an ambulance in the middle of the night. In the morning, the young carer called the YCI staff in a panic alerting them there was no food in the house, prompting an immediate home-visit by the program director. Upon assessing the situation, the staff discovered that there were a variety of frozen food options available, but the child did not know how to prepare them.

More recently, the program has begun piloting dedicated "family nights" in which both children and their families are invited to attend events. Workshops for the adults include topics such as finances, wills, powers of attorney etc. and for the children there are traditional young carer programing workshops, often geared towards respite/entertainment. With the aim of reducing barriers to involvement, the rollout of whole-family programming has been "crucial in letting the entire family open up and talk" (Program Director: YCI).

A dual assistance and mitigation-based intervention exists with the development of a 'Youth Advisory Group' that enables interested young carers the opportunity to contribute ideas to the types of programming offered while participating in awareness workshops and conferences organized by the staff. As a case in point, the group was recently involved in a conference funded by the YCI and attended by an audience of researchers, local community agencies, educators, and young carer families. Here, the youth put on a dramaturgical performance of "what it means to be a young carer" which not only provided them access to peer support (assistance) but helped reduce some of the long-term negative educational and social impacts of their caregiving by developing their organizational and public speaking skills (mitigation). Finally, additional mitigation-based services include respite-based outings, the most popular of which being the free, week-long March and summer break camping excursions. As the program director reveals:

> For some of these kids, when they are anticipating the summer, it's not 'yay summer is almost here' but instead it starts to create anxiety because they're going to be home 24-7.

The broader revelation that respite, more generally, is rare for young carers was reiterated by staff who also affirmed the need to extend programming to include events aimed at "giving these kids a break to just do something fun" in addition to those with therapeutic and informational goals.

Hospice Toronto's Young Carer Program (YCP) provides a similar, though smaller scale, model of assistance and mitigation-based programming for young carers across the GTA. As expressed by the program manager, the overriding goal of the program is to "connect young carers with other young carers so they know they are not alone in their experience…and that alone creates a sense of normalcy since they feel disconnected from other peers". Providing access to a peer support group, therefore, is of paramount importance and is further augmented by the provision of information and/or referrals for services not provided by the program.

Dual assistive and mitigation-based services include respite outings and workshops geared at developing self-help strategies to be used outside of the program, ranging from weekly and monthly programming for both 'YCP Teens' (designed for teenagers) and 'YCP Kids' (for kids 12 and under) which include monthly outings (e.g. sports events, movie nights) and 'All About' workshops that provide additional information for youth about their family member's condition through age-appropriate, non-threatening activities and medical play. Referrals to additional counselling and/or therapeutic-based services are also a necessary provision given the significant emotional stress and depression observed among the program users. As recounted by the program manager, "children as young as nine years old show symptoms of disordered eating which makes sense as it's often the result of feeling the need for control…and we do see more of that within our kids".

Providing advocacy for young carers within the school system is another important (mitigation-based) service provided by the program. Here, staff liaise with educational personnel when young carers require added accommodation at school, for example with their frequent absences and need for deadline extensions. Helping to educate administrative and teaching staff of the broader issue of youth-based caregiving is another component of this outreach initiative:

> Many teachers or other staff were often unaware of why the kids were struggling at school or why they were often late and it was assumed that the child was uninterested in school or just a quote on quote 'bad student' (YCP Program Manager).

Along these lines, the program manager recounted how one pair of siblings were continually getting in trouble for having their cell phones on during class time, with teachers failing to understand that the parent was at home on survival equipment that, if malfunctioned, would require the youth to rush home and/or call 911. Finally, a lunchtime program was piloted in one Toronto school for staff to provide young carer programming but a siphoning of interest from both school staff and administration led to the program having just over a three-month run. In particular, staff reported difficulties on two fronts: (1) in gauging the level of need from teachers who were asked to complete and return information sheets probing classroom need, and (2) receiving back parental consent forms required for those youth under the age of 18 to participate in the program.

Finally, the *Cowichan Young Carers Program* has taken a slightly different approach than the Ontario-based programs, with a dual assistance and mitigation-based goal geared at involving young people in a leadership capacity to build awareness on the issue, particularly within schools. As the founding program director revealed, "we realized very early on that the program had to be youth-driven and that in order for it to be meaningful, we had to involve youth, especially those in a caregiving role". The resulting Youth Resource Team (YRT) comprised of the program director, local youth (both young carers and non-carers) and a handful of adult volunteers resulted in: (1) the production of a documentary film (Ending the Silence) and a curriculum guide for educators, both of which are available for purchase by schools and community organizations; (2) more than 80 presentations made to various local schools, community organizations and public officials; (3) a youth-based conference (with young caring being the underlying theme) that drew in an average of 100 students from ten neighbouring schools, and (4) a consultative role in the 2013 Action Canada Task Force (2013) dedicated solely to raising awareness for young carers.

Assistance-based services in the form of counselling or respite-based referrals is another feature of the program. As communicated by the founding program director, the substantial stress and isolation many of these youth experience from providing "round the clock" caregiving has led to referrals for suicide prevention counselling in two instances and substance abuse counselling in another two instances. As similarly revealed in Chapter Five, staff reveal that youth are largely unaware that their substance use is problematic, with one such case recounted of a female young carer using a family member's prescription drugs to help relieve stress yet completely unaware that doing so was dangerous. Temporary respite-based referral services involving coordination with the local island health authority is another service offered to help give youth a break in cases where they need to attend a school or social event. In these instances, temporary in-home supervision visits from a personal support worker or nurse are arranged for the young person's care-receiver. However, issues linked to the significant paperwork involved combined with the fear of having a stranger come into the home prevented their wider uptake. Indeed, the fear that telling an authority figure might lead to separation of family members, has been found to contribute to many vulnerable families keeping their family situations hidden (Cass et al., 2009; Moore & McArthur, 2007). Unlike the other two programs, however, most of the assistance and mitigation based services are provided by external organizations through referrals due to staffing and funding shortages that limit the provision of such in-house programming. Acknowledging these limitations, the founding director made the decision to allocate the majority of financial and human resources to awareness-raising missions. This also helps explain the much lower number of 50 youth cited earlier as accessing in-house support services relative to the YCI Powerhouse Project (700) and Toronto-based YCP (500).

Mentorship pairings provide an additional dual assistance-mitigation service offered by the program, with more senior young carers helping out those more junior young carers going through similar life events. One such example is the case of a young adult carer, who looked after his father until his father had passed away, mentor one of the younger male carers in the group whose mother was dying of brain cancer. These types of in-group mentorship relationships are noted as key in reducing the stigma attached to youths' caregiver status:

> Many of them (young carers) felt very isolated because there's this stigma about being a caregiver that means that there is something wrong with their family and that it wasn't a normal family so having other caregivers around who understood what they were going through was a big relief (Founding program director).

One very important and distinct mitigation-based gain made by the Cowichan program has been the collaboration with the local school board (District 79) to allow for a volunteer course credit allowance for YRT members dedicating 100 hours or more to the program (which included those hours attending the bi-weekly program meetings). Not only is this a factor declared vital by staff for enabling some young carers to graduate high school but it also provides the program with a steady stream of both non-caregiving and caregiving youth volunteers. Pursuant to this, a commitment of even 30 hours by any YRT member would satisfy their provincial-based volunteer-work graduation quota (applicable to both Ontarian and British Columbian high school youth), with many YRT members completing both their volunteer work quota and receiving a full course credit with their involvement in the program.

On the whole, despite each program offering services geared at both helping the young person cope and providing limited respite and/or educational assistance, none have the operational capacity to function at a *preventative* level. A preventative level would require a whole-family approach catered to each individual family that invariably requires wider collaboration amongst a variety of social, health and disability service providers. The current Canadian healthcare mandate of concentrating on the needs of the care-receiver alone, versus those of the care receiver *and* their caregivers, effectively eliminates such an approach from taking off the outset.

6.5.2. Barriers to program expansion and/or improvement

The largest issue facing all three programs involves their inability to move past an assistance-mitigation-based level of programming. To recap, *preventative* strategies focus on avoiding the entrenchment of a young person's caring role by providing support to the family when a disability or chronic illness first manifests itself or, alternatively by creating an optimum combination of formal and informal support tailored individually to each family where a young carer exists (Purcal et al., 2012). Presently, a preventative model is blocked due to two key issues surrounding: (1) a lack of stable and sufficient funding, and (2) the difficulty in creating collaborative partnerships with local school boards.

6.5.2.1 Funding

All three of the program staff raise similar concerns surrounding the lack of stable and sufficient funding and how that impacts the scope and reach of their programming. As it relates directly to the larger NPSS, this can be seen as resulting from policy changes targeting funding protocols and the transition towards “project-funding” regimes (Gibson, O’Donnell & Rideout, 2007). Previously, governments provided long-term public or “core-funding” commitments to many non-profit organizations which allowed them to cover their basic administrative and organizational costs in addition to those required in running the programs. Towards the late 1990’s and into the first half of the 2000s, however, a “funding crisis” occurred which resulted in the state and other private funders moving away from core funding towards project and/or outcome-based funding (Struthers 2013, p.11). These shorter duration grants produce a unique financial vulnerability among organizations that are now put in a process of perpetual application and re-application for time-sensitive, project-specific funding. Cash-strapped organizations are under increasingly strict accountability protocols, whereby staff are expected to collect data as a way of measuring “output” or assessing outcomes. To be sure, those staff interviewed in this study unanimously note how the collection of such data is very time consuming, taking up a sizeable amount of time that could otherwise be devoted to delivering additional services to young carers.

The reorienting of NPSS funding reflects broader neoliberal policies grounded in New Public Management (NPM) ideals. Ushered in most feverishly by conservative political movements, the application of NPM to the public sector is an increasingly global phenomenon emphasizing a shift from traditional public administration to public “management” based on practices borrowed from the private sector. Key tenets of NPM include the decentralization of various forms of management within the public service (e.g., the creation of autonomous agencies and devolution of budgets and financial control), an increasing use of markets and competition in the provision of public services (e.g., contracting out and other market-type mechanisms) and an added emphasis on performance, outputs and customer orientation (Larbi, 1999). Applying these and other for-profit enterprise strategies to the Canadian public sector enables the state to successfully off-load a range of health and social care services to the unpaid household and community sector. This became particularly evident with the 2000 federal implementation of “accountability regimes” popularized by NPM (Gibson, O’Donnell & Rideout, 2007).

Certain factors have influenced the move towards NPM. First, government budgets that purportedly could not continue to spend as much money as before on social services were cut; second, the public’s alleged lack of confidence in public services led to a twofold expansion of public-private partnerships (PPP’s) and the sub-contracting out of services to the NPSS; and third, the idea that government policies were no longer entirely domestic matters but instead had far-reaching implications beyond our national economy (Aucoin in Gibson, O’Donnell & Rideout, 2007). The overwhelming result was the widespread contracting out of social services once provided by the state to the NPSS as a method of lowering the costs associated with its public provisioning, while concomitantly reducing the size of the state, evading public-sector unions, and enabling governments to manage results via a hierarchical system of governance.

Problematically, instead of the state allocating additional funding to the NPSS in order to ease their uptake of once publicly provided services, the opposite occurred as evidenced with the shift from core to project-specific funding. The effects of these dual processes on the Canadian non-profit community sector have not gone undocumented. Phillips and Levasseur (2004) reveal how organizations in the NPSS are now required to engage in more detailed reporting to meet the increased accountability measures imposed on them by the state. Under these circumstances, organizations may be less likely to take risks with new projects, fearing that their funding may be revoked. Further, community organizations may begin tailoring services to funders’ visions rather than to their clients’ needs. Additionally, delays in the funding approval process leads to frequent problems with cash-flow and the carrying out of projects (Phillips & Levasseur, 2004). Richmond and Shields (2005) similarly note the added burden placed on staff due to new accountability regimes and the organizational mission ‘drift’ that can occur when the commercialization of operations compromises the organization’s autonomy. Gibson, O’Donnell and Rideout (2007) corroborate these findings while highlighting additional consequences related to forced partnerships, contract hirings, and the added use of information and communications technologies. Consistent among all of these studies is how such shifts benefit government and private funders by compromising the autonomy, work experiences and operational capabilities of staff and volunteers in the NPSS. Examining how restructuring operates in the three organizations included in this sample helps clarify their current inability to deliver more comprehensive young carers supports.

For Hospice Toronto’s Young Carers Program, an initial multi-year grant enabled the program to launch based around dedicated service ‘deliverables’ including the youth-specific programming described earlier in addition to the development of a ‘Young Carer Toolkit’ that could be replicated nationwide. When that initial funding expired and was not renewed “due to cutbacks unfortunately”, staff were forced to engage in the frequent application of a patchwork of more precarious, shorter-term grants from a variety of different business and charity funding “pockets”. Due to the shorter duration of these new project-specific funds, staff cited the continual need to seek out and apply for funding, the process of which was noted as time-consuming and often prohibitive. At the time of interview, three current grant applications were underway. Understandably, when asked what the largest barrier to expanding the program was, both the program director and operating manager pinpointed the “lack of continuous funding” and the ripple effect it had on staffing, space issues and the range and scope of available programming.

First, funding has only been able to accommodate an average of 2.5 paid staff to run a host of programs and workshops for well over 500 youth over in its five-year run, with staff increasingly hired on shorter-term contracts in order to account for shorter-term "project" funding. In the past two years, three new program managers have rotated in and out of the position, revealing the impacts of shorter-term employment contracts that work against the retention of a more permanent managerial base. The reliance on volunteers is cited as crucial to executing workshops, especially the respite-based outings and camps. Despite the added volunteer help, staff note feeling "pretty stretched" to maintain the existing level of programming and admit an inability to expand on certain types of programming that youth express preference for, particularly more costly day outings or weekend trips. As an example, the success of a recent "leadership retreat" weekend in Muskoka for teenage young carers was met with unanimous requests "wishing it could be a week-long" (YCP Program Manager). The staff similarly recognize the importance of such extended respite-based programming:

> That type of programming allows for those deeper connections to be developed and it's something that is really needed but unfortunately, it's something we are not able to guarantee because we just don't have the resources (YCP Program Manager).

Funding shortages are also cited as the main reason for multiple office re-locations. A ripple effect of such time-consuming moves is a further reduction of staff time necessary to deliver scheduled programming and the occasional cancelling of events. Acutely aware of the limitations with not having a permanent and sufficiently sized home base, the staff express a palpable sense of disappointment with not being able to "provide young carers and their families with a permanent location which works towards creating a parent connection that feedback shows is highly valued" (YCP Manager).

The Cowichan Young Carers Program similarly note funding challenges, principally related to the lack of necessary resources to hire additional staff to deliver more assistance-based services. Recognizing early on that such funding and staffing issues would limit their ability to provide such programming, the founding director apportioned available resources on raising awareness and creating a dialogue within local schools and the wider community. The subsequent curtailment of self-help and respite-based programming was lamented by staff, especially given the awareness that such service gaps were particularly hard felt amongst the large contingency of "First Nations kids who really need the support but could not get it" (Founding Program Director). In light of Chapter Four's revelation that it is those areas of Canada with the greatest proportion of indigenous persons (i.e. Northern Canada) that have the greatest proportion of young carers, the finding that a large number of Aboriginal youth require their services is unsurprising. Funding shortages also prevent the direct provisioning of financial aid to those "young carers belonging to families who were in near poverty situations". As revealed by the founding director of the program:

> Many (young carers) said they would appreciate some financial support on two levels: One, they don't have time for part-time jobs so they are not gaining on those skills needed to be employable in their futures but two, they are not getting the money that they need from those jobs (Founding program director).

Comparing the three organizations, the YCI: Powerhouse Project has had the most stable funding since start-up, resulting from multi-year project grants in addition to "base" funding from the Local Integration Health Network (LHIN) and the Alzheimer Society of the Niagara Region (ASNR). The difference between the YCI Powerhouse Project and the Toronto and Cowichan programs, financially, is evident in the scope and reach of their programming. For one, the YCI has been able to keep a core staff of six employees on hand while providing additional perks that the other groups cannot budget for, including the provision of meals for young carers during programming and the payment of cab fares and/or staff vehicle gas costs to bring those young carers without transportation to and from program events. This was especially important for those young carers deemed to be “in need”, a designation typically provided to young carers in families where the adult lost their vehicle or the ability to drive resulting from either financial difficulties or the nature of the parental illness. Families with severely physically disabled children were also designated “in need” due to the challenges resulting from getting to and from young carer programming:

> We hear from parents that to load the kids up in the car to drop the young carer off to the program to then take the other sibling back home, unload them and then load them back in the car to repeat the process again two hours later once the programming was over at 8’oclock at night ended up triggering disaster for the kid (with the disability). [YCI Program Director]

This transportation allotment available to assist such families with added difficulties not only increases their young carer participant reach but enables those in some of the most precarious financial (and non-financial) situations to attend programming. While staff acknowledge this feature as integral to assisting some of their more vulnerable young carers, it is nevertheless mentioned as one of the greatest barriers to expanding the program given its hefty annual expenditure of roughly $25,000. Second, the success in securing long-term “core” funding from the LIHN in 2008 (under the “Aging at Home” initiative) funded the retention of two permanent home-base offices. These two locations are large enough to accommodate drop-in visits and weekly workshops (one in Niagara, one in Haldimand-Norfolk) and serve as a hub for young carers and their families to connect. Notwithstanding the advantages of possessing more generous and stable LIHN funding, neoliberal strings attached to financing reveal themselves in the form of time-consuming “deliverables” consistent with for-profit business models. A significant burden for existing staff, a substantial portion of the program director’s time is dedicated to producing and disseminating “proof” of the program’s efficacy, the process of which is met with a palpable sense of discomfort:

> We feel like we have to prove ourselves and show what we’re doing with the money and why we deserve the money…we have to report everything monthly…I send in (to the LIHN) financial reports, stats reports, hourly reports of staff time and then quarterly I have to send more detailed reports with a narrative about what we did during the last quarter, attendance to programs, types of programs, partnerships and various charts but I also include family testimonials about what our people say …because we’re not just stats, we are people and what the people say is important! (Program Director)

Interjecting first-hand parental and young carer testimonials in the required reports – a feature not mandated by the more quantitatively-oriented focus of the deliverables – was a deliberate move against the perceived cold and impersonal accounting of an otherwise highly personal and people-oriented program.

Even with the YCI’s funding advantage, the program director was quick to note that additional staff is required given the geographical spread of their young carers and the inability to provide resources in each of their surrounding neighbourhoods. Staff were thus “constantly looking for granting ideas” required to expand their reach and subsequently plan for the added human (staffing) resources required for such an expansion. Securing smaller, shorter term “project” funding was not an easy task given interviewees’ admission that many such grants stipulate narrower parameters for how the funds can be spent (e.g., to fund programming). As such, it was necessary to “deliberately strategize” how to acquire various grants (e.g., a summer camp grant from the Niagara Community Foundation and other small grants from groups such as the Kiwanis and Rotary clubs of St. Catharines). Part of this process involves a significant amount of the program director's time dedicated to "relationship building". Visiting potential funding groups and providing presentations about the program in the hopes of securing additional supplementary funding is part and parcel of this process, the successful efforts of which are noted to "really help the program size" (i.e., the number of young carers program users they are able to assist).

An important catch-22 regarding the acquisition of funding, however, is the fact that a program's ability to secure additional funding is directly proportional to the number of staff on hand. Having three times the number of staff relative to the other programs increased the YCI's ability to seek out such additional funding sources without directly compromising staff time dedicated to the actual delivery of programing. This staffing advantage made all the difference to increasing the scope and range of programming options made available to YCI young carers.

6.5.2.2 Integration with schoolboards

Given that young carers tend to spend the majority of their time either at school or at home, the value of establishing awareness and programming within schools is a factor repeatedly deemed necessary by staff. In line with the findings from Chapter Five, in addition to global research revealing that young carers are reluctant to take breaks or socialize, because they feel they should stay home and help around the house (Barry, 2011; Cass et al., 2009), frontline staff are cognizant that evening and weekend programming means additional time spent away from the household, which at times is stressful for the young carer. Taking programming to the schools is therefore viewed as a win-win for frontline staff and young carers alike; however, gaining access is the key issue to seeing this goal through. With the exception of the Cowichan program, the main issues experienced with the Ontarian programs are twofold, with difficulties first connecting with administrative staff to gain entry and second, in connecting with individual teachers to gauge potential student need/eligibility.

The issue of "red tape" was a recurring complaint, with staff noting instances whereby entry to the school was granted to provide informational events (e.g. advocacy assemblies) but development of in-house programs were halted due to the lack of turnaround for required parental consent. Contributing to this educational blockade, of course, is the lack of widespread information or public awareness on young carers and the benefits of such programming. This poses a source of frustration for frontline staff and educators, who despite identifying interested young carers, could do nothing to help without parental consent for students under the age of 18.

The Cowichan program, in contrast, was able to successfully gain entry to a range of schools, primarily due to a particularly supportive superintendent who acted as a gatekeeper into the local school board. With that added help, the program director and members of the Youth Resource Team (YRT) were able to raise public awareness through dozens of presentations across a wide range of local schools. Additionally, the development of a course credit allowance for eligible members of the YRT worked both to facilitate a steady stream of caregiving and non-caregiving youth volunteers into the program while easing parental concerns related to their child's involvement. Together, these educational components added legitimacy to the program and its mission but also facilitated a greater turnaround in the necessary parental consent forms required for youth participation in the program. Unfortunately, educational and young carer program staff and resource shortages prevented the delivery of in-house programming within the schools. This was additionally identified by the founding director as a key issue limiting future growth:

> One of the next stages that needs to happen is that these support groups need to be held in schools because so many of these kids have so much going on, usually related to caregiving, but if it was at lunchtime, then it would work.

The potential benefits of collaborating with schools to expand young carer supports are known to all those interviewed in this study, beneficial in both expanding available programming but also mitigating some of the negative educational consequences incurred. As the YCP program manager notes, many young carers require age-differentiated accommodations to prevent falling behind:

> In the elementary schools, a lot of the kids are constantly late or need to be dismissed from school early and the teachers are sometimes unaware of the reasons why and are unaccommodating for that….in high school, a lot of kids are needing the support in terms of being late and needing to leave early as well, but also may have troubles studying for a test or focusing at school because they are worried about what's going on at home and need extensions.

Group work is another significant obstacle for young carers due to their lack of free time outside of school hours with which to meet with peers, resulting in their being "marked down on those types of things" (Program Manager: YCP). For some young carers in the Cowichan program, the decision was made to drop out of school altogether or to transfer to alternative programs that could better accommodate their need for added flexibility:

> Being in the regular system required them (young carers) being at school all day, every day, and then do homework at night and that was too much for them and they would either drop out or find alternative programs.

The value of extending supports to the schools is clear; however, difficulties in anchoring community-based initiatives in educational institutions extend beyond merely those cited in this study. In the wider literature, roadblocks to launching such initiatives include: impenetrable (educational) bureaucracies that are difficult to work with (Campbell & Erstein, 201); limited training for teachers in working in a team and with atypical children and difficulties in scheduling time for collaborative planning (Hillier, Civetta & Pridham, 2010); schools' fear of scrutiny due to years of preexisting negative media coverage and high levels of burnout among educational staff (Kohl, 1997), and unresolved issues of information sharing and territorialism on the part of community organizations (Crowson & Boyd, 1993; Mawhinney, 1994).

When such partnerships do work, however, they have been shown to hold promise for advancing child and youth priorities. In the United States, successful *youth development coalitions* serve the interests of various at-risk youth via collaborative partnerships between local community, health care, and educational groups. As Campbell and Erbstein (2010) reveal in their analysis of seven such community youth coalitions in the Sacramento-area, it is possible to move from a disconnected set of youth programs to a coordinated system with greater policy relevance. One such coalition targeted the reduction of teen pregnancy by working with schools and community-based organizations to implement policy changes, including the provision of family life classes in earlier grades (Campbell & Erbstein, 2010). Project SUCCESS (Schools Using Coordinated Community Efforts to Strengthen Students) targeted the reduction of substance use among adolescents by placing highly trained professionals in schools to provide a range of prevention and early intervention services (National Crime Prevention Centre, 2009). Geared to high-risk students aged 12 to 18, this collaborative program launched in 1995 and now operates in 38 states (National Crime Prevention Centre, 2009).

In Canada, similar youth-focused initiatives exist but remain rare and fail to include caregiving as a potential marker of *risk*. The Substance Abuse and Youth in School (SAYS) Coalition, for example, brings together fifteen organizations including four local school boards, youth-focused addiction treatment agencies, enforcement, and allied professionals. Together, they have been able to enhance communication and develop, resource and implement a comprehensive drug and alcohol abuse prevention and treatment program for students in grades 7 – 12 across Ottawa (Ottawa Network for Education, 2016).

The rarity of such collaborations at the Canada level is largely attributed to the 20-year period of educational reform involving the introduction of measures aimed at reducing education expenditures. Specifically, the amalgamation of school boards and centralization of funding amidst increases in accountability measures (via new provincial curriculum, outcomes-based education and standardized testing) has led to an intensification of public sector teachers' work that leaves little time left for such inter-sectoral partnerships (Chan, Fisher, & Rubenson, 2007; Lessard & Brassard, 2009; Sattler, 2012; Ungerleider & Levin, 2007). With that said, a promising point for follow-up research could involve the interview of educational staff in order to better flush out those barriers to launching and sustaining such youth-centered coalitions.

6.6 CHAPTER CONCLUSION

Using qualitative interview data with frontline staff at each of the three Canadian young carer programs, this research aimed to review the range of services offered to young carers while documenting those barriers to improving their scope and reach. Findings reveal that available support services for young carers in Canada can be characterized as both assistance and mitigation-based in nature, with programming aimed at both assisting youth in their caregiving roles (via counselling, information on other services or self-help techniques and access to peer support groups) or mitigating some of the negative consequences incurred (via respite-based services, educational assistance and training and employment assistance).

While the three programs have worked diligently to incorporate many of the best practices operating in the United Kingdom, they are still constrained from moving to a model of prevention which works against the entrenchment of a young person's caring role and the documented negative outcomes corresponding with it. Specifically, a preventative model of young carer programming would include a personalized, whole-family approach that is currently impeded by two factors: (1) the lack of stable and sufficient funding resulting from an increasingly neoliberal approach to health and social services delivery within Canada and, (2) the inability to gain adequate entry into local schools with which to provide in-house (lunchtime and/or after-school) young carer programming.

With young carer program staff having little influence over the diminishing funding sources available to them (and the larger NPSS), attempts to create programming partnerships with local schools has been a practical strategy worth pursuing. Cost efficiencies aside, program staff are acutely aware that many young carers feel a sense of guilt and social exclusion due to their commitment to their families, which restricts their mobility outside of their households and/or schools. The extension of programming to the schools, therefore, is not simply cost-efficient but the logical next step for young carer service providers. Despite all three programs working to gain entry into local schools with which to implement in-house programming during lunch and afterschool time-slots, issues related to administrative pull-back and difficulty obtaining parental consent restricts their success. Only one of the three programs successfully gained entry into the local school board and this was due primarily to a supportive superintendent. Due to funding and staffing shortages, however, this access resulted primarily in awareness-raising efforts and in securing school credits for program involvement. Providing the crucial in-house lunch and after-school period programming was not possible.

Finally, the scope and reach of young carer programming was shown to be directly proportional to the amount of funding procured by each organization, with additional funds leading to both a wider range of services offered and a larger number of young carers able to access them.

Regardless of inter-agency funding differences, program staff unanimously note the difficulty in securing sufficient funding which results in a constant struggle to seek out supplementary capital, often in the form of short-term project-based grants. As researchers in the NPSS have noted, the increasing need to replace services cut by the state, combined with the shift from core funding to project-funding has resulted in a "stressed-out social service environment, where organizations continue to attempt to provide adequate services while being underfunded" (Gibson, O'Donnell & Rideout, 2007, p. 32). Barring a return of core-funding to the NPSS, young carer service providers will need to find alternative ways of securing the necessary funding to support an ever-growing contingent of Canadian young carers.

Most importantly, these larger funding roadblocks are shown to link up to recent neoliberal-inspired restructuring initiatives, indicative of advanced global capitalism and the corresponding politics of retrenchment that reduce the role of the Canadian welfare state and its delivery of health and social care services. Decisions to rely on informal care are tied to constraints at the intra-familial and policy-level, with the state holding significant power to reduce youth-based caregiving by funding, providing and regulating formal care services. If we look to the whole-family approach that operates in the United Kingdom, for example, we may see how a more holistic method of assessing and providing for the needs of vulnerable families can circumvent the entrenchment of a young person's caring role while reducing the negative outcomes associated with it. Currently, such a whole-family approach stands in contrast to the existing individualized approach operating in Canada. Instead, the transition from hospital to home-care alongside the current mandate of health and social services to provide support primarily to the care recipient, operate in tandem to enlist a growing number of children and youth into a reserve army of reproductive labour. Putting a spotlight on the power of the state to impact both the incidence of youth-based caregiving and the supports dedicated to it is therefore crucial.

It is no longer tenable to continue glossing over the growing demands placed on families to manage the care of their loved ones, especially among dual-earner families where one or more member(s) have a chronic illness or disability. Failing to address and provision for such shifting care relationships, mainly the added reliance on children and youth to satisfy unmet reproductive care needs, will lead to additional problems down the road. As accurately articulated by the director of Hospice Toronto's YCP:

> If we continue to look the other way and not address the impact caregiving has on these youth now, we will have to deal with it down the road as secondary users of a physical or mental health care system.

Efforts to promote recognition for young carers continue. Better methods at identifying, supporting and ultimately preventing their entrenchment in substantial caring roles are required.

CHAPTER SEVEN

Dissertation Conclusion

7.1 SUMMARY OF KEY FINDINGS

The overriding purpose of this dissertation was to document the experiences and needs of young carers while locating their care within a broader moment of change unfolding across modern Western Civilization. To that aim a multimethod design comprised of three separate empirical studies worked towards achieving four broader research goals set out by this research.

This dissertation starts by providing an overview of the factors contributing to the increases in youth-based caregiving across Canada. Building off the historical works of Aries (1962), Postman (1982) and Zelizer (1985), the fluid and socially constructed nature of childhood was demonstrated, in addition to the joint economic, political, demographic and socio-cultural factors contributing to its revaluation. Specifically, linking broader societal change fueled by globalization to a new era of familial fragility provided the lens with which to understand the need for a growing proportion of families to rely upon on the help of their children to fill the (unpaid) reproductive labour shortages previously fulfilled by stay-at-home mothers and wives. Pursuant to this, the resulting shift from the previously normative 'emotionally priceless and economically useless' child (Zelizer, 1985) to an emerging postmodern 'emotionally priceless *and* reproductively useful' archetype was shown to be the natural corollary of factors including (but not limited to) an ageing population, wider welfare state retrenchment under neoliberalism, changing family types and the strong presence of women in the labour market under globalization.

Next, a statistical account of youth-based caregiving was provided using national survey data. Here, the first known trend analysis of youth-based caregiving in Canada was offered by way of census (1996-2006) and GSS (2012) data. In the first phase of analysis, census data was used to demonstrate how Canadian young carers represent one of the largest global young carer groups, with 1.18 million youth between the ages of 15 and 24 providing some level of unpaid care in 2006, representing a 13.5% increase from 1996 to 2006. The majority of youth were shown to provide unpaid care to other children compared to seniors, with over 100,000 youth providing 15 or more hours of weekly unpaid care to children compared to another 20,792 providing 20 or more hours to seniors. Significant provincial variation was also shown to exist, with a staggering 46% of youth in Northern Canada (i.e. Yukon, Northwest Territories and Nunavut) providing some level of unpaid care in 2006 compared to a low of 25.8% for Quebec youth. In line with the adult-based care literature, females accounted for the majority of young carers and there was an increasing feminization of care as youth aged, the differences of which were most acute at the highest care levels. Finally, the interplay of gender and marital status revealed compounding effects, with those married or common-law females providing an alarming majority of care within their families, despite not having young children in their households.

In the second phase of analysis, GSS data from cycle 26 (2012) was used to provide an updated and more nuanced (albeit less representative) portrait of youth-based caregiving since 2006. Doing so revealed an increase to the number of young carers, with over 1.25 million Canadian youth aged 15 to 24 providing unpaid caregiving in the context of illness, disability or aging in 2012. This larger figure stands despite the GSS failing to enumerate Northern Canada, a region the previous census data analysis revealed to be important for youth-based caregiving. Second, and similar to the census results, the majority of youth were shown to provide under five hours of unpaid caregiving per week. Third, and dissimilar to the census results, a greater proportion of youth were providing 15 or more hours of weekly care, revealing a greater burden of care for those providing care in the context long-term illness or disability. Courtesy of the added detail provided by the GSS, a fourth key finding highlighted all that care provided to nonrelatives. Despite the majority of youth-based care provided to relatives, particularly grandparents, over 11% of youth were providing care to non-relatives, a cohort of care-receivers outstripping the cumulative care provided to brothers *and* sisters. This was an important revelation given that it remains an entirely overlooked area in the existing domestic and global young carer literature which focuses primarily on familial caregiving. The reasons behind the provision of non-relative care were also unique, with the majority of care provided to close friends (the largest group of non-relative care-receivers) and in the context of mental illness. Fifth and final, the continued power of gender and marital status in decisions surrounding care was evident when looking at those married and common-law females. Indeed, women in this census family arrangement continue to provide the vast majority of care compared to those single, never married youth. Gender was also shown to impact the choice of care receiver and the types of caregiving tasks provided, with youth prone to caring for persons of the same-sex (the differentials strongest among non-relative care) and to provide gendered care tasks paralleling findings from the adult-based caregiving literature.

The second overriding research goal was unearthed via a qualitative approach that probed the first-hand experiences of young carers. Here, focus group research was used in order to address the current paucity of first-hand accounts of youths' caregiving in the Canadian literature. Grounding the experiences of youth in Daly and Lewis's (2000) 'social model of care' underlined how the care provided is not only labour, but labour provided in a normative framework of obligation and love and that carries with it pecuniary and non-pecuniary costs. Thematic analysis of the results revealed the complex and often contradictory nature of youth's caregiving, with three sets of dichotomous themes found relating to: (1) High versus Low caregiving; (2) Recognition versus Rejection; (3) Benefit versus Penalty, and (4) Approach versus Avoidant coping.

First, young carer's level of care was shown to exist in a bimodal pattern, with youth taking on either age-appropriate, low-level caring roles that can be seen as a natural and normative part of adolescence or high-level, episodically parentified roles that increased their vulnerability vis-à-vis their short and long-term development. Second, young carers displayed a simultaneous desire for recognition alongside the rejection of their carer status (i.e. through secrecy and/or denial). In this sense, young carers rather consistently praised the efforts of understanding adults and peers with whom they confided in or sought assistance from. Yet they also took great pains to hide their caregiving at times out of fear and/or embarrassment. Third, although young carers demonstrated exceptional maturity and resilience in the face of added responsibility, they incurred a unique form of 'Young Carer Penalty' that differs from the historically gendered "care penalty" first developed by England and Folbre (1999) to highlight the sacrifices adult women make as caregivers. Specifically, compared to more traditional modes of adult-based caregiving, youth-based caregiving was shown to entail added constraints and penalties linked to the life-course stage of the carer, with adults better able to exercise control over their care work due to added financial, legal and maturational advantages. Moreover, the added propensity to withhold their distress and reject their caring roles out of fear and embarrassment further constrained youth's ability to seek out dedicated supports in a crucial period of personal (i.e., familial, social, emotional) and professional (i.e., educational and employment-based) development. Fourth, and in line with the paradoxical and complex nature of youth's caregiving, participants were shown to practice both approach and avoidant style coping. At times, young carers faced their added burden head on by utilizing a range of healthy and proactive strategies to manage their added stress or responsibility.

Other times, they resorted to counterproductive and potentially dangerous methods of avoidance that potentially carry forms of short- and long-term harm.

The final overriding research goal was explored via in-depth interviews with a purposive sample of frontline staff at each of the three existing Canadian young carer programs. Here, the goal was to explore the supports presently available for young carers and the challenges to increasing their scope and reach. Building off a framework provided by Purcal et al., (2012) for categorizing young carer supports, Canadian young carer services were found to be both 'assistance' and 'mitigation-based' in nature. They were aimed primarily at: (1) assisting youth in managing their caregiving roles (via counselling, information on other services or self-help techniques, and access to peer support), and (2) mitigating some of the negative consequences incurred (via respite-based services, educational assistance and training and employment assistance). Furthermore, the ability of staff to expand their current scope and reach to offer more 'preventative' programming was impeded by two key factors: (1) lack of stable and sufficient funding due to broader neoliberal-inspired cutbacks to the nonprofit and community sector and, (2) the inability to gain adequate entry into local school boards with which to provide in-house (lunchtime and/or after-school) programming.

Taken together, when comparing the level of supports available to young carers in the United Kingdom – the most advanced model of young carer awareness and social programming – only 1 in 1000 young carers access caregiver supports in Canada compared to the roughly 1 in 14 doing so in England and Wales. This is the case despite 432,250 young carers aged 5–25 years documented to provide unpaid care in England and Wales in 2011 (Association of Directors of Adult Social Services Association of Directors of Adult Social Services, 2014) compared to the over 1.25 million youth aged 15 to 24 doing just that in Canada.

7.2 STRENGTHS AND LIMITATIONS

The strengths of this dissertation are fourfold and are tied to the choice of multimethod design.

First, by amalgamating the young carer literature with those found in Sociology (i.e., Childhood Sociology, Sociology of Care and Work and Family) and Social Psychology (i.e., parentification), I was able to fill out their respective deficits and extend the discourse surrounding children's labour to include caregiving motivated by chronic illness and disability but also by practical and financial necessity fueled by increasing familial fragility. Taking a socio-historical approach to the issue also unearthed why the development of young carers, as a special category of discourse and policy development, has gained momentum during this era of macro-societal challenge and change.

Second, the quantitative leg of my research highlighted those key issues to consider when relying on existing national datasets to assess youth-based caregiving while simultaneously providing the first known statistical overview of the matter the national level. It also provided supporting evidence for global studies using similar national data to explore youth-based caregiving while unearthing novel findings not previously reported in the literature. Furthermore, working with both datasets and comparing their respective strengths and weaknesses highlighted important areas for improvement that may render future care-based survey instruments more effective. The most important of these suggestions revolved around the need to survey youth of all ages and over a broader, less context-specific range of care circumstances.

Third, the qualitative leg of this dissertation filled in additional gaps in the Canadian young carer literature. Speaking with young carers themselves provided crucial first-hand accounts of their experiences and needs, that apart from two exceptions (Nichols et al., 2013; Toporas, 2005), was missing from the Canadian literature. The second set of qualitative interviews with frontline staff at the three existing Canadian young carer programs allowed me to document the range of supports available to Canadian young carers while documenting their barriers to growth and/or improvement.

Fourth and last, my positionality as a previous young adult carer helped increase the soundness of my qualitative data by enabling a unique rapport to be developed with my subjects. Interjecting my first-hand experiences with caregiving during the focus group discussion and solo interviews, as well as with the parents of potential participants helped to put my subjects at ease in order to share their personal stories without fear of judgment or reprisal.

Notwithstanding its benefits, my research also has its limitations. First, my purposive sample of young carers affiliated with an existing young carers program meant that only the experiences of a particular sub-group of young carers were captured – mainly those formally identified as carers and receiving dedicated supports with which to manage their caregiving. Arguably, these youth represent a distinct category of young carers who provide unpaid reproductive labour in the context of familial illness or disability, rendering them in line with the traditional group of children and youth focused on in the young carer literature. Consequently, the findings may overestimate the experiences of youth providing some of the more time-intensive and personal care tasks (i.e., the administration of medicine and bathing/dressing) relative to those youth providing other forms of more instrumental reproductive labour (e.g., cleaning, cooking, and sibling care) in the context of familial fragility. Also underestimated in the findings are all those youth who provide care to nonrelatives, an important cohort of youth shown to exist as per the GSS analysis.

Finally, the impressive resilience many young carers displayed in coping with their added stress and responsibility may be tied to their involvement with their young carers program. In the absence of interviewing those young carers not affiliated with a young carers program, we cannot be sure whether all young carers are equally resilient in their coping or whether those more hidden/invisible young carers experience a heightened young carer penalty resulting from their exclusion from such targeted professional support. Drawing on a broader sample of young carers, particularly those more hidden young carers not receiving such added supports, is required to strengthen the wider transferability[31] of this study's results.

Second, the decision to use national survey data, necessary to produce the prevalence estimates, came with a set of limitations that were outside of my control. Despite the census representing the best source of nationally representative data in Canada, conceptual and operational limitations led to a substantial undercount in the actual number of Canadian young carers. Specifically, the enumeration of only those persons aged 15 years or older in addition to the capture of only those care tasks provided to either children or seniors leaves out all those persons under the age of 15 years and all the care they provide to adults, particularly parents. With the removal of the unpaid work module from the census post 2006, the GSS (cycle 26, 2012) provided the next and most useful survey to probe unpaid caregiving in more depth. Moreover, its sole dedication to 'Caregiving and Care Receiving' enabled the topic to be explored in substantially more depth than the census; however, its failure to enumerate persons from Northern Canada (i.e., Yukon and the Northwest Territories) renders it ineligible as a substitute for the census to provide national estimates. A final limitation of both data sources is the increased risk of underreporting due to issues surrounding fear or stigma as well as the wider under-reporting of unpaid care tasks due to the failure to view such work outside of normal exchanges of family life.

---

[31] Transferability is one of the four aspects of "Trustworthiness", a widely used set of criteria for evaluating qualitative data analysis first developed by Lincoln and Guba (1982). The specific aspect of Transferability represents the notion of external validity, or generalizability in quantitative research.

Third, there were some topics that arose within the group discussion that could have benefited from one-to-one interviews rather than the focus group design. When probing the consequences of care, as an example, one participant noted her struggles with anorexia, depression and anxiety disorder. Given the group context and the sensitive nature of these experiences, the matter was not probed in more depth although it certainly would have been in a one-to-one interview format.

7.3 RECOMMENDATIONS

With the topic of this dissertation representing a relatively unchartered but emerging area of scholarly interest in Canada, this study was able to amass various recommendations related to the following three areas: research, policy and programming.

7.3.1 Research

Stepping back and reviewing all of the strengths and limitations of this dissertation helped to stress three areas for follow-up research.

First, although my particular sample of young carers represented a group traditionally outlined by the young carer literature, it left out those more hidden young carers that have yet to be identified as young carers and receive assistance. Indeed, one of the most significant challenges to identifying young carers is locating them, a common struggle noted to occur among young carer researchers and one that is further hindered in countries with little public awareness of the issue. The task going forward is to find more creative ways to draw in those currently hidden young carers as well as the varying sub-groups discovered in Chapter Five (i.e., those providing care to non-relatives) and those providing reproductive labour in the context of familial fragility. Six prospective options that exist to cast a wider net of young carers and unearth additional findings include: (1) collaborations with school boards; (2) improving existing national surveys; (3) multicultural, multiregional and multinational (3M) survey research programs; (4) a whole-family approach to research, (5) the use of targeted sampling to tease out potential racial and/or cultural pulls to youth-based caregiving, and (6) the use of longitudinal research designs.

First, collaborations with school boards to include caregiving questions in their respective ‘student censuses’ is one such technique to gaining access to a representative sample of children and youth. The Toronto District School Board, for example, began surveying its student base in 2006 to “provide information on who our students are and how they felt about their lives inside and outside of school” (TDSB, 2013). Adding a caregiving module to these surveys would help to draw out more hidden young carers not affiliated with young carer programs while also alerting school officials of the need to account for this added labour within their educational policies.

Second, improving upon existing large-scale national surveys to address their limitations is also required to increase the reach of enumerated young carers. The most crucial and necessary redress involves the re-instatement of a new and improved unpaid care module to forthcoming long-form censuses that enumerates youth of all ages and care provided to all individuals (not simply seniors or children). Second, a minimum decennial repeating of cycle 26 of the GSS is necessary to provide the added detail unavailable from any potentially revived long form census care questions. Certainty, in the absence of any forthcoming care questions reinstated to the long-form census, the repetition of cycle 26 of the GSS will be crucial in providing a rough benchmark for future care statistics.

Third, added potential in providing more reliable and valid cross-national comparative data on the topic lies with multicultural, multiregional and multinational (3M) comparative survey research. Comparative surveys date back to the mid-1930s, most famously with the Strategic

Bombing Surveys conducted by the U.S. Government in Germany and Japan during the Second World War. Today, the practice has become more sustained and sophisticated with a wide range of ongoing survey projects representing multiple nations and even associations of countries such as the European Community (Harkness et al., 2010; Smith, 2010). Major types of 3M surveys range from those global general social science collaborations like the International Social Survey Program, to global general population studies on specialized topics like the International Mental Health Stigma Survey, to those more specialized appendages such as the European Working Conditions Survey (Smith 2010, 479). Developing a 3M Young Carers Survey Research Project would provide an excellent opportunity to bring international experts together to produce a single survey instrument that best measures youth-based caregiving and the unique cross-national experiences and consequences incurred by such children and youth.

Fourth, utilizing a whole-family approach to studying youth-based caregiving can help fill in some of the existing data gaps. Throughout each stage of my research, various issues were noted, including the limited scope of survey data sources and/or missing or incomplete data when probing areas outside of youth's knowledge base (e.g., total household income). Taking such a whole-family level approach to the investigation of reproductive labour more broadly, but children's reproductive labour specifically, will add a level of detail currently absent from existing research. For one, it can shed added light onto the main care dyad in question (i.e., the relationship between the young carer and the care-receiver), in addition to understanding the young carer's place within a larger coordinated care effort. Indeed, highlighting the individual roles played by various persons involved in such wider care "networks" is a point reiterated by Fast & Keating (2000) in their policy research agenda for family caregiving scholarship (p. 14). One particular qualitative design that naturally possesses a whole-family approach and that could be useful in prospective studies is that of ethnographic research. Sociologists such as Annette Lareau (2003) and Marianne Cooper (2014) have provided in-depth ethnographic accounts of families that if applied to this research could have helped reduce some of the methodological issues noted above. Lareau shadowed 12 diverse families for about a month, aiming for "intensive 'naturalistic' observation" of parenting habits and family culture while Cooper observed and conducted 100 interviews with members of 50 families in Silicon Valley over a two-year period. Barring the heightened issues of access and reactivity when requesting extended time with young carer families in their homes, a naturalistic in-house observation of the family unit can provide the currently missing family level data required for further analysis, such as income, age and employment status of each member. It can also provide crucial information as to how families negotiate care-work among members and how such decisions differentially impact various family members.

Fifth, additional targeted sampling can help shed light on how youth-based caregiving is mediated by race and or cultural affiliation. Although this particular sample failed to discover cultural or ethnic differences in the provision of care, widening the sample and better probing the effects of cultural kinship patterns will be useful. The only cultural connection uncovered in this particular study involved the use of prayer as a coping mechanism for two Muslim young carers. For both participants, their strong faith and active use of prayer to deal the stress of their caregiver role was explicitly stated. Although none of the remaining sample participants overtly indicated an impact of race or ethnicity on their decision to provide care (or how much care to provide), it is likely that these relationships exist and simply need to be focused upon in subsequent interviews. Stratifying future focus groups based on racial or ethnic affiliation could be one such strategy to help flush out the impact of such factors in youth's participation with unpaid caregiving.

Sixth and last, longitudinal research designs are needed to correct for the limitations inherent in existing cross-sectional research. By focusing on the experiences and impacts of child and youth-based caregiving at a specific point in time, the existing hub of cross-sectional scholarship fails to expose the long-term impacts of children and youth's caregiving. Implementing longitudinal, ideally panel methods (following the *same* young carers over time) that track young carers from childhood to adolescence to adulthood can better isolate the impacts of such reproductive care labour on young carers' future development and well-being. For example, by tracking how limited labour market experiences and educational interruptions in childhood impact future educational and professional labour market prospects, these types of studies can provide data on the actual (versus projected) long-term costs of youth's caregiving.

Relatedly, we can also explore how children and youth's caregiving impacts future career trajectories, by assessing whether the care-based career aspirations align with their actual future occupational paths. Those that do indeed extend such experiences with early caregiving into their later occupational trajectories may experience greater success and fulfillment in their adult-based careers. It may also be the case, however, that their caring roles within the home limited their exposure and opportunities to pursue other areas that were not merely an extension of their caring roles in childhood. Without following these youth into adulthood, or conducting retrospective interviews with adults who were at one point young carers, the question of whether this worked out to be a benefit or challenge remains uncertain. Longitudinal panel designs can also shed light as to how various statuses, such as marital, impact youth's level of caregiving as they age into more traditional gender roles of wife/common-law partner and/or mother. Although the use of retrospective cohort studies of adults who were young carers in the past have tried to get at some of these long-term effects, they too are limited by memory recall issues and other biases when relying on historical accounts. Only by following young carers overtime as they pass through various life-course stages can we truly assess the long-term benefits and harms sustained by such early caregiving.

7.3.2 Policy and Programming

Just as my progression through this dissertation highlighted areas for future research, it pinpointed areas for policy creation and programming expansion. The two invariably go hand in hand, as the lack of legislative backing for young carers in Canada is directly connected to the lack of funding set aside to support them. Notwithstanding this reality, four areas of policy and programming that require modification are as follows.

First, children and youth need to be officially recognized within policy and legislation as a legitimate source of unpaid caregivers. Existing federal funding must be provided to extend caregiver supports to include children and youth and not be rooted solely in income tax credit programs geared towards working adults. We have much to learn, for example, from the Care Act operating in the United Kingdom, where youth and adults alike have legal rights as carers which provides them a choice of direct monetary allowances or access to a wide range of public services geared towards supporting their caregiver needs. Promoting awareness for the issue additionally requires involvement of all levels of federal, provincial and municipal government. The online 'carer self-assessment' tool found on the U.K.'s National Health Service (NHS) website is but one such tool that can better inform all persons of their rights and/or local support services.

Second, creating multi-sectoral collaborations among health, educational and social service providers can better locate the many children and youth noted to exist on the periphery of their services. In the United Kingdom, for example, the Whole-Family approach to federal young carer policy has led to numerous collaborations among various state and community-based networks that aim not only to identify but also to refer young carers to available supports. One idea that may achieve such an aim across Canada involves expanding current intake procedures for health and community sector professionals to probe for the presence of young carers. In Ontario, for example, 14 Community Care Access Centers (CCAC's) oversee the delivery of home-care across the province yet no consideration is given to the needs of the primary caregivers who invariably assist the home-care recipient. As it pertains to young carers specifically, intake assessments could document the presence of young carers during initial and ongoing assessments and provide program support referrals to those found to exist. Promoting linkages between CCACs and young carer program staff could then be extended to include educational, public health and/or policy networks. Examples of such successful U.K.-based collaborative efforts arising from such multi-sectoral collaborations include: (1) the development of Young Carer ID cards that alert adults, particularly teachers, about young carers' added responsibilities so to be granted the necessary allowances regarding deadlines and absences, and (2) the placement of dedicated educational staff ('Young Carer Leads') in schools to support young carers within their continuing professional development. At the very least, there needs to be a more comprehensive mechanism put in place to share information of the issue and the regional assistance available to young carers amongst the full range of child and youth practitioners.

Third, and as revealed in my interviews with young carer staff, there is a desperate need to expand available young carer support services within schools and beyond. The finding that a combined total of roughly 1,250 young carers have received assistance from Canadian young carer programs reveals a massive unmet need and the necessity of establishing supports across all provinces, especially in Northern Canada where the highest proportion of young carers exist but where no dedicated young carer programs presently operate. Indeed, all young carer program staff participants agree that instituting dedicated programming within the schools is the crucial next step to reaching a wider base of eligible children and youth while also helping to inform educators of their unique needs. Expanding young carer programming across Canada, however, must go hand in hand with increased federal funding to both healthcare and social services but also to the educational sector since both parties of this inter-sectoral partnership must have the adequate monetary and nonmonetary resources in order to successfully launch and sustain such coalitions. The funding crisis documented by young carer program staff located the broader issue within neoliberal-inspired initiatives aimed at eliminating more stable "core-funding" in favour of shorter-term and insecure "project-funding" tied to time-consuming quantitative accountability measures.

Fourth, better supporting adult caregivers and reinstating lost healthcare services will serve a preventative function to the number of child and youth caregivers providing more substantial caregiving loads. For one, the lack of standardized legislation granting all employees more flexible and generous family leave certainly promotes the conscription of youth into unpaid caregiving once their parents' limited work leaves expire. Targeting Canada's workplace legislation, which is primarily a provincial jurisdiction, therefore needs to ensure minimum standards to protect workers with caregiving commitments (Bernier, 2015). Additionally, available Caregiver Tax Credits offer only small deductions to the amount of one's taxable income for a "financially dependent family member" which benefits only a small minority of caregivers, mainly those higher earning caregivers with a *live-in* child or grandchild aged 18 years or older. The strict requirements for such tax credits amount to a situation where, despite women being the vast majority of caregivers, available credits are claimed primarily by men and are completely inaccessible to low income caregivers (British Columbia Law Institute, 2010, p. 73). Moreover, these tax credit schemes also exclude the growing number of seniors and chronically ill adults choosing to live at home as long as possible, even if their condition limits their autonomy (Turcotte, 2014). With that said, financial aid for all caregivers should be configured away from their present non-refundable (income tax) nature into more refundable and generous, social assistance-style alternatives that render eligible a wider and more evidence-based group of caregivers (i.e., those relative and non-relative caregivers of any age, irrespective of residency to the care-receiver). Indeed, failing to provide more comprehensive and direct income supports that adequately address the income loss incurred by family and community caregivers explains the need to draw on all possible sources of unpaid child and youth care labour.

While these recommendations provide just a brief overview of some of the issues inherent with adult-based caregiver supports, they highlight two key points. First, short of their massive overhaul and the coterminous expansion of homecare, nursing care and supportive services commensurate with the rising number of care-receivers, efforts at limiting or eliminating child and youth-based caregiving will be partial at best. The state holds substantial power to limit inappropriate or burdensome child-based caregiving by sufficiently providing supports for families with unmet care needs. Coming back to the claims raised by disability rights scholars, particularly those referring to the problems inherent with the shifting of focus away from the disabled or ill family member to the caregiving child or youth, obfuscates the underlying problem of poverty and lack of support which forces some disabled parents to solicit inappropriate assistance from their children (Keith & Morris, 1995; Olsen, 1996; Olsen & Parker, 1997). There is also the real risk that legitimizing and normalizing youth's caregiving will enable the neoliberal state apparatus to offload further care onto the community given this "new" reproductive unpaid labour source. Second, underlying these roadblocks to more effective management of unpaid, reproductive care labour is the broader-level social, economic, political and cultural change ushered in by neoliberalism under advanced global capitalism. Ultimately, increases to youth-based caregiving are tied to the increasing strain experienced by Canadian families and in this context, children and youth are experiencing more fluid and transformative childhood trajectories as a result. The post-World War II "golden age" of secure wages, low unemployment, high fertility and stable nuclear family structures has passed. The once secure and steady reserve army of unpaid reproductive labourers (i.e., stay-at-home wives and mothers) that once managed the vast majority of all familial caregiving not satisfied by the state has also passed. In modern global capitalist society, most families have now fully deployed all available members into wage work, leaving children and youth to experience an unfair and disruptive "tax" by spending their time as family caregivers while their parents hang on to their labour market positions (Duffy & Pupo, 2015). On top of the increased labour market involvement of parents, there is a greater concern than ever before for the future stability of their children, and rightly so amidst pressures of income insecurity, youth unemployment, surging home and educational costs and declining incomes (Duffy & Pupo, 2015).

Although this dissertation focused on the consequences of familial fragility on younger family members, the reality is that there is an overlying need to address the growing fragility experienced across all age and lineage lines. Only then, can we appreciate the full set of processes expediting families, particularly mothers', need to draw upon the reproductive labour of their children.

7.4 CONCLUDING REMARKS

This dissertation explored the growing trend towards youth-based caregiving in Canada by targeting three overarching goals related to its prevalence, policy and practice. Of the most valuable take-away messages from this research is how the current invisibility of young carers in Canada is not attributable to their low prevalence or current unmet needs, but to the wider societal inability to view children as both providers *and* receivers of care. Taking a socio-historical approach to the rising incidence and attention paid to the issue thus allowed for a more comprehensive understanding of how, for growing number of Canadian children and youth, the result of ongoing macro-economic and noneconomic change has been the more recent revaluation of their childhoods to an emerging 'emotionally priceless *and* reproductively useful' archetype.

More importantly, compared to adults, whose care-work is a socially accepted and expected part of life, that same reproductive labour provided by children and youth is often disregarded by their rendering as incompetent, dependent and non-productive 'kids' which contributes to the active rejection and/or concealment of these caring roles. While many young carers displayed remarkable maturity and resiliency in handling their added care obligations, the extensive 'young carer penalty' documented to exist poses serious threats to their current and future well-being and development. Consequently, it becomes our social responsibility to help raise awareness for these children and youth and to help secure more accessible supports in their communities. Without helping to mitigate (ideally, prevent) children and youths' long-term entrenchment in substantial caring roles, and the coinciding risks involved, we are complicit in denying them of their full current and future potential.

Finally, what has probably been the most surprising revelation while conducting this research are the many "ah-ha" moments from those becoming privy to my research and/or findings over the course of this dissertation. Whether at academic conferences or during informal conversations with friends and relatives, nearly every person that I have spoken to seems to know of at least one young carer in either their personal or professional circles. Most often, I hear this from elementary school teachers who recount instances of similar vulnerable children and youth in their classrooms. None of them, however, have heard of the term ‘young carer’ or are aware that similar youth around the world are being supported by their governments as official caregivers. All of them wish that they can do more to help but none of them know how or where to start. My hope is that this dissertation will be a starting point to doing just that.

REFERENCES

Abbey, S., & O'Reilly, A. (1998). *Redefining motherhood: Changing identities and patterns*. Toronto, ON: Canadian Scholars' Press.

Acker, J. (1990). Hierarchies, jobs, bodies: A theory of gendered organizations. *Gender & society,* 4(2), 139-158.

Acker, J. (2004). Gender, capitalism and globalization. *Critical sociology,* 30(1), 17-41.

Action Canada Task Force. (2013). *Who Cares About Young Carers? Raising Awareness For An Invisible Population. Action Canada*. Retrieved from http://www.actioncanada.ca/en/fellows/projects/20122013-who-cares-about-young-carers-raising-awareness-for-an-invisible-population/.

ADASS (Association of Directors of Adult Social Services). (2014). *Census 2011 Briefing-Age Statistics*. London: ADASS.

Agnew, R. (2001). *Juvenile Delinquency; Causes and Control.* Los Angeles, CA: Roxbury Publishing Company.

Akyeampong, E. B., & Usalcas, J. (1998). *Work absence rates, 1980 to 1997.* Statistics Canada Catalogue No. 71-535-MPB, 9. Ottawa, ON: Statistics Canada.

Albo, G. (2009). The crisis of neoliberalism and the impasse of the union movement. *Development Dialogue*, 51, 119-131.

Albo, G. (2010). The "New Economy" and "Capitalism Today". In N. Pupo & M. Thomas (Eds.), *Interrogating the New Economy: Restructuring Work in the 21st Century* (pp. 3-20). Toronto, ON: University of Toronto Press.

Aldridge, J., & Becker, S. (1993). Punishing children for caring: The hidden cost of young carers. *Children & society,* 7(4), 376-387.

Aldridge, J., & Becker, S. (1996). Disability rights and the denial of young carers. The dangers of zero-sum arguments. *Critical social policy*, 16(48), 55-76.

Aldridge, J., & Becker, S. (2003). *Children Caring for Parents with Mental Illness: Perspectives of Young Carers, Parents and Professionals*. Bristol: The Policy Press.

Anderssen, E. (Jun 5, 2013). The great, untapped household labour pool: your kids. *The Globe and Mail.* Retrieved from http://www.theglobeandmail.com/life/parenting/the-great-untapped-household-labour-pool-your-kids/article12363913/

APS Group Scotland. (2010). *Getting it Right for Young Carers. The Carers Strategy for Scotland, 2010-2015.* Edinburgh: Scotland.

Ariès, P. (1965). *Centuries of childhood. A social history of family life*. New York, NY: Vintage.

Armstrong, P. (1996). The feminization of the labour force: Harmonizing down in a global economy. In I. Bakker (Ed.), *Rethinking restructuring: Gender and change in Canada*, (pp. 29-54). Toronto, ON: University of Toronto Press.

Armstrong, P. (2003). *Wasting Away: The Undermining of Canadian Health Care*. Toronto, ON: Oxford University Press.

Armstrong, P., & H. Armstrong. (2005). Public and Private: Implications for Care Work. *Sociological Review*, 53(2), 167–187.

Armstrong, P., & Armstrong, H. (2010). *The double ghetto: Canadian women and their segregated work. Updated Third Edition*. New York, NY: Oxford University Press.

Armstrong, P., & Connelly, M. P. (1989). Feminist political economy: An introduction. *Studies in Political Economy*, 30, 5-12.

Armstrong, P. & Kits, O. (2001, April). *One hundred years of caregiving*. Ottawa, ON: Law

Commission of Canada.

Auerbach, L. (2002). *Issues raised by Public Private Partnerships in Ontario's hospital sector.* Ottawa, ON: Canadian Health Coalition.

Baago, S. (2004). The unrecognized caregiver: Children of dementia. *Perspectives,* 27, 3-4.

Baago, S. (2005). *Inside the developmental 'Black Box' of young carers, a literature review prepared for the Young Carers Initiative Niagara*. Toronto, ON: Ontario Trillium Foundation.

Baethge, M. (1989). Individualisation as hope and as disaster: Contradictions and paradoxes of adolescence in Western societies. *International Social Science Journal,* XXXVII,(4), 441-454.

Baines, D., Cunningham, I., Campey, J., & Shields, J. (2014). Not Profiting from Precarity: The Work of Nonprofit Service Delivery and the Creation of Precariousness. *Just Labour,* 22, 74-93.

Bakker, I. & Gill, S. Eds. (2003). *Power, production and social reproduction*. New York, NY: Palgrave Macmillan.

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 and counselling*, 30(3), 229-246.

Barber, M. & Siskowski, C. (2008). Youth Caregivers: Unrecognized Providers of Care. *Pediatrics,* 121, 873.

Barling, J., Kelloway, E. K., & Frone, M. R. (Eds.). (2004). *Handbook of work stress*. Thousand Oaks, CA: Sage.

Barnett, B. & Parker, G. (1998). The parentified child: early competence or childhood deprivation? *Child Psychology and Psychiatry Review*, 3, 146-166.

Barnetson, B. (2010). Effectiveness of Complaint-Driven Regulation of Child Labour in Alberta. *Just Labour*, 16, 9-24.

Barnetson, B. (2011). Children Working Alone in Alberta: How Child Labour and Working Alone Regulations Interact. *Just Labour,* 17-18, 34-48.

Barrington-Leigh, C. P. (2013). The Quebec Convergence and Canadian Life Satisfaction, 1985-2008. *Canadian Public Policy*, 39(2), 193-219.

Barry, M. (2011). 'I realised that I wasn't alone': the views and experiences of young carers from a social capital perspective. *Journal of Youth Studies*, 14(5), 523-539.

Beaujot, R., Du, C. J., & Ravanera, Z. (2013). Family Policies in Quebec and the Rest of Canada: Implications for Fertility, Child-Care, Women's Paid Work, and Child Development Indicators. *Canadian Public Policy,* 39(2), 221-240.

Beck, U. (1992). *Risk Society: Towards a New Modernity.* London, Sage.

Becker, S. (1995). *Young carers in Europe: an exploratory cross-national study in Britain, France, Sweden and Germany.* Young Carers Research Group. Loughborough, Leics: Loughborough University.

Becker, S. (2007). Global Perspectives on Children's Unpaid Caregiving in the Family. *Global Social Policy,* 7(1), 23-50.

Becker, S. (2000). *'Young Carers'* in M. Davies (ed.). The Blackwell Encyclopedia of Social Work (p. 378). Oxford, UK: Blackwell.

Becker, S., & Becker, F. (2008). *Young Adult Carers in the UK: Experiences, Needs and Services for Carers Aged 16–24*. Essex: The Princess Royal Trust for Carers.

Benach, J., & Muntaner, C. (2007). Precarious Employment and Health: Developing A

Research Agenda. *Journal Epidemiol Community Health,* 61(4), 276–277.

Bernard, A. (2015). *Youth Labour Force Participation: 2008 to 2014*. Statistics Canada Catalogue No. 11-626-X. Ottawa, ON: Statistics Canada.

Bernard, A., & Branch, A. S. (2013). *Unemployment Dynamics Among Canada's Youth*. Statistics Canada Catalogue no. 11-626-X. Ottawa, ON: Statistics Canada.

Bernier, N.F (2015, June 11). Canada needs a national Strategy for Unpaid Caregivers. *The Huffington Post. (Op-Ed)*. Retrieved from http://www.huffingtonpost.ca/nicole-f-bernier/canada-unpaid-caregivers_b_7553950.html

Bezanson, K., & Luxton, M. (2006). *Social reproduction: Feminist political economy challenges neo-liberalism*. Montreal, QC: McGill-Queen's Press-MQUP.

Bilsborrow, S. (1992). 'You Grow Up Fast as Well…' Young Carers on Merseyside. *Health and Social Care,* 1(5), 315-318.

Bittman, M, Fisher, K, Hill, T, Thompson, D & Thomson, C. (2004). *Reaching isolated carers: contacting carers with unmet needs for information and support*. Sydney: Social Policy Research Centre, UNSW.

Boesveld, S. (2014, August 11). Child labour or just chores? Debate rages after Saskatchewan bans kids from working on family farm. *The National Post.* Retrieved from http://news.nationalpost.com/news/canada/debate-rages-after-saskatchewan-bans-kids-from-working-on-family-farm

Boszormenyi-Nagy, I. & Spark, G.M. (1973). Invisible Loyalties: Reciprocity in *Intergenerational Family Therapy.* Hagerstown, MD: Harper & Row.

Brewer, J., & Hunter, A. (1989). *Multimethod research: A synthesis of styles*. Newbury Park, CA: Sage.

British Columbia Law Institute (February, 2010). *Care/work: law reform to support family caregivers to balance paid work and unpaid caregiving / a study paper prepared by the British Columbia Law Institute & Canadian Centre for Elder Law*. Study Paper No.4. Vancouver, BC: British Columbia Law Institute.

Broad, D., & Hunter, G. (2009). Work, Welfare and the New Economy: The Commodification of Everything. In N. Pupo & M. Thomas, (Eds.), *Interrogating the new economy: Restructuring work in the 21st century* (21-42). Toronto, ON: University of Toronto Press.

Broszormenyi-Nagy, I., & Spark, G.M. (1973). *Invisible loyalties: Reciprocity in intergenerational family therap*y. Hagerstown, MD: Harper & Row.

Brown, E.M. (1989). *My Parent's Keeper: Adult Children of the Emotionally Disturbed.* Oakland, CA: Harbinger Press.

Brown, L. (2013, December 20). Ontario high school students struggle to get their volunteer hours. *The Toronto Star*. Retrieved from https://www.thestar.com/yourtoronto/education/2013/12/20/ontario_high_school_students_struggle_to_get_their_volunteer_hours.html

Bryman, A. (2006). Integrating quantitative and qualitative research: how is it done? *Qualitative research*, 6(1), 97-113.

Bryman, A., & Burgess, B. (Eds.). (2002). *Analyzing qualitative data*. Abingdon, OX: Routledge.

Budig M.J., & England, P. (2001. The wage penalty for motherhood. *American Sociological Review*, 66, 204-25.

Burchell, B., Ladipo, D., & Wilkinson, F. (Eds.). (2005). *Job insecurity and work intensification*. New York, NY: Routledge.

Bynner, J. M., & Roberts, K. (Eds.). (1991). *Youth and work: Transition to employment in England and Germany*. London: Anglo-German Foundation for the Study of Industrial Society.

Byrne, J., & Humble, A. M. (2007). An introduction to mixed method research. Atlantic Research *Centre for Family-Work Issues*, 1-4.

Campbell, D. T., & Fiske, D. W. (1959). Convergent and discriminant validation by the multitrait-multimethod matrix. *Psychological bulletin,* 56(2), 81-105.

Campbell, J., Bruhm, G. & Lilley, S., (1998). *Caregivers' support needs: Insights from the experience of women providing care in rural Nova Scotia*. Halifax, NS: Maritime Centre for Excellence for Women's Health.

Campbell, L. D., & Martin-Matthews, A. (2003). The gendered nature of men's filial care. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences,* 58(6), S350-S358.

Campbell, D., & Erbstein, N. (2010). *Benefits and Challenges in Building a Community Youth Development Coalition*. REACH Issue Brief Series. Number One. Sacramento, CA: Sierra Health Foundation.

Canadian Centre on Substance Abuse. (2007). *Substance Abuse in Canada: Youth in Focus.* Ottawa, ON: Canadian Centre on Substance Abuse.

Canadian Index of Well Being: CIW. (June 2010). *Caught in the Time Crunch: Time Use, Leisure and Culture in Canada: Special Report*. Waterloo, ON: University of Waterloo.

Canadian Institute for Health Information: CIHI. (2011). *Health Care in Canada, 2011: A Focus* *on Seniors and Aging.* Ottawa, ON: CIHI. Retrieved from https://secure.cihi.ca/free_products/HCIC_2011_seniors_report_en.pdf

Canadian Paediatric Society (2008). Teens and sleep: Why you need it and how to get enough. *Paediatrics & Child Health.* 13(1), 69-70.

Carers Australia. (2002). *Young carers research report: Final report*. Canberra: Department of Family and Community Services.

Carers NSW. (n.d). *Young Carers.* Sydney: Carers NSW. Retrieved from https://www.carersnsw.org.au/how-we-help/support/yc/

Carers UK. (2014). Assessments and the Care Act: Factsheet. London: Carers UK.

Carrière, Y., & Galarneau, D. (2011, October 26). *Delayed retirement: A new trend.* Statistics Canada Catalogue No. 75-001-X. Ottawa, ON: Statistics Canada.

Cass, B., Smith, C., Hill, T., Blaxland, M., & Hamilton, M. (2009). *Young carers in Australia: Understanding the advantages and disadvantages of their care giving*. FaHCSIA Social Policy Research Paper #38. Canberra: Department of Families, Housing, Community Services and Indigenous Affairs. https://www.dss.gov.au/sites/default/files/documents/05_2012/sprp_38.pdf

Cassidy, T., Giles, M., & McLaughlin M. (2014). Benefit finding and resilience in child caregivers. *British Journal of Health Psychology*, 19, 606-18.

Castells, M. (2011). *The power of identity: The information age: Economy, society, and culture (Vol. 2*). Oxford: John Wiley & Sons.

Chai, C. (2015, April 30). Canadian millennials hit hardest by mental health woes: poll. *The Toronto Star.* Retrieved from http://globalnews.ca/news/1968775/canadian-millennials-hit-hardest-by-mental-health-woes-poll/

Chalmers, H. (2011, June). *Powerhouse program evaluation report: 2010–2011 Programming year*. Waterloo, ON: Young Carers Initiative, Powerhouse Project. Retrieved from http://powerhouseproject.ca/wp-content/uploads/2013/07/2010-2011-quality-assurance-summary1.pdf

Chalmers, H., & Lucyk, L. (2012). The impact of caregiving: Is it who I am or what I do? *Relational Child & Youth Care Practice*, 25, 37–46.

Chan, A., Fisher, D., & Rubenson, K. (Eds.) (2007). *The evolution of professionalism: Educational policy in the provinces and territories of Canada.* Vancouver, BC: UBC Centre for Policy Studies in Higher Education and Training.

Chappell, N. L. (2011). *Population aging and the evolving care needs of older Canadians.* Montreal, QC: Institute for Research on Public Policy (IRPP). Retrieved from http://www.irpp.org/pubs/IRPPstudy/IRPP_Study_no21.pdf.

Chappell, N. L., & Kusch, K. (2007). The gendered nature of filial piety – A study among Chinese Canadians. *Journal of cross-cultural gerontology,* 22(1), 29-45.

Charles, G. (2011). Bringing young carers out of the shadows. *Reclaiming Children and Youth*, 20, 26–30.

Charles, G., Stainton, T., & Marshall, S. (2008). Young carers in Canada: An invisible population. *Relational Child and Youth Care Practice,* 21, 5–12.

Charles, G., Stainton, T., & Marshall, S. (2009). Young carers: Mature before their time. *Reclaiming Children and Youth*, 18, 38–41.

Charles, G., Marshall, S., & Stainton, T. (2010). Demographics profiles and initial results from the British Columbia Young Carers Study. *Relational Child and Youth Care Practice,* 23, 64–67.

Charles, G., Stainton, T., & Marshall, S. (2012a). Young Carers in Immigrant Families: An Ignored Population. *Canadian Social Work*, 12(1), 83-92.

Charles, G., Stainton, T., & Marshall, S. (2012b). *Young carers in Canada: The hidden costs and benefits of young caregiving*. Ottawa, ON: Vanier Institute of the Family.

Charlesworth, L.W. & Rodwell, M.K. (1997). Focus groups with children: a resource for sexual abuse prevention program evaluation. *Child abuse & neglect,* 21(12), 1205-1216.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative Analysis*: A Practical Guide through Qualitative Analysis. London: *SAGE Publications Ltd*.

Children's Society. (2013). *Hidden from view: The experiences of young carers in England*. London: The Children's Society.

Christensen, P.H. (2004). Children's participation in ethnographic research: Issues of power and representation. *Children and Society*, *18*, 165-176.

Christensen, P., & James, A. (Eds) (2008). *Research with Children. Perspectives and Practices*. New York, NY: Routledge.

Clawson, D. (2003). *The next upsurge: Labor and the new social movements*. Ithaca, NY: Cornell University Press.

Clay, D., Connors, C., Day, N., Gkiza, M., & Aldridge, J. (2016). *The lives of young carers in England. Qualitative report to Department for Education*. (DfE Research Report 499). London: Department for Education.

Cluver, L., Operario, D., Lane, T., & Kganakga, M. (2012). "I can't go to school and leave her in so much pain": Educational shortfalls among adolescent 'young carers' in the south african AIDS epidemic. *Journal of Adolescent Research, 27*(5), 581.

Cohen, R. (2001). Children's contribution to household labour in three sociocultural contexts: A southern Indian village, a Norwegian town and a Canadian city. *International Journal of Comparative Sociology*, 42(4), 353-367.

Colombo, F., Llena-Zozal, A., Mercier, J., & Tjadens, F. (2011). *Help Wanted? Providing and Paying for Long-Term Care.* OECD Health Policy Studies: OECD Publishing. Retrieved from http://www.oecd.org/els/health-systems/help-wanted-9789264097759-en.htm

Comacchio, C. R. (1999). The infinite bonds of family: Domesticity in Canada, 1850-1940 (Vol. 4). Toronto, ON: University of Toronto Press.

Comacchio, C. (2006). *The dominion of youth: Adolescence and the making of modern Canada, 1920 to 1950 (Vol. 8*). Waterloo, ON: Wilfrid Laurier University Press.

Condor, S., & Gibson, S. (2007). Everybody's Entitled to their Own Opinion: Ideological Dilemmas of Liberal Individualism and Active Citizenship. *Journal of Community & Applied Social Psychology* 17(2), 115-140.

Connor-Smith JK, Compas BE, Wadsworth ME, Thomsen AH. & Saltzman H. (2000). Responses to stress in adolescence: measurement of coping and involuntary stress responses. *Journal of Consulting and Clinical Psychology*, 68(6), 976-92.

Cooper, M. (2014). *Cut adrift: families in insecure times*. Berkeley, CA: University of California Press.

Cornish, M. (2016). *Every Step You Take*. *Ontario's Gender Pay Gap Ladder.* Canadian Centre for Policy Alternatives (CCPA) ISBN 978-1-77125-275-1.0. Toronto, ON: CCPA.

Corsaro, W. A. (1997). *The sociology of childhood*. Thousand Oaks, CA: Pine Forge Press.

Cranford, C. J., Vosko, L. F., & Zukewich, N. (2003). The gender of precarious employment in Canada. *Relations Industrielles/Industrial Relations, 58(3),* 454-482.

Cranswick, K., & Dosman, D. (2008). *Eldercare: What we know today*. Canadian Social Trends Catalogue No. 11-008-Z. Ottawa, ON: Statistics Canada.

Cree, V. E. (2003). Worries and Problems of Young Carers: Issues for Mental Health. *Child and Family Social Work,* 8 (4), 301–309.

Cressey, P. (1932). *The taxi-dance hall.* Chicago, IL: University of Chicago Press.

Creswell, J. W., & Clark, V. L. P. (2007*). Designing and conducting mixed methods research*. Thousand Oaks, CA: Sage.

Creswell, J.W., Clark, V.L.P., Gutmann, M.L., & Hanson, W.E. (2003). In A, Tashakkori & C. Teddie (Eds.). *Handbook of mixed methods in social & behavioural research* (pp. 209-240). Thousand Oaks, CA: Sage.

Crompton, S., & Vickers, M. (2000). *One hundred years of labour force*. Statistics Canada Catalogue No 11-008. Ottawa, ON: Statistics Canada.

Crowson, R. L., & Boyd, W. L. (1993). Coordinated services for children: Designing arks for storms and seas unknown. *American Journal of Education*, 101(2), 140-179.

Cudahy, B. J. (2006, September-October). *The containership revolution: Malcom McLean's 1956 innovation goes global.* TRF News 246: Transportation Research Board. Retrieved from http://onlinepubs.trb.org/onlinepubs/trnews/trnews246containerrevolution.pdf

CUPE Research Report. (2011, April). *P3 Hospitals: The wrong direction.* Ottawa, ON: Canadian Union of Public Employees. Retrieved from http://cupe.ca/sites/cupe/files/p3_hospitals_-_executive_summary-0.pdf

Daly, M., & Lewis, J. (2000). The concept of social care and the analysis of contemporary welfare states. *The British journal of sociology*, 51(2), 281-298.

Davidson, K., Arber, S., & Ginn, J. (2000). Gendered meaning of care work within late life marital relationships. *Canadian Journal on Aging*, 19, 536–553.

Davis, J. M. (1998). Understanding the meaning of children: A reflexive process. *Children and Society*, 13, 325-335.

Dearden, C., Aldridge, J., Newton, B. and Becker, S. (1994). *Getting it Right for Young Carers: A Training Pack for Professionals*. ISBN 0-907274-12-9. Loughborough: Loughborough University.

Dearden, C., & Becker, S. (1997). Protecting young carers: legislative tensions and opportunities in Britain. *Journal of Social Welfare and Family Law*, 19(2), 123-138

Dearden, C. & Becker, S. (2002a). *Young Carers and Education*. London: Carers UK.

Dearden, C., & Becker, S. (2002b). *Young Carers Projects: What Do CCFR Evaluation Reports Tell Us About Dedicated Projects For Young Carers*? London: Carers UK.

Degler, C. N. (1980). *At Odds: Women and the Family in America from the Revolution to the Present.* New York, NY: Oxford University Press.

Dempsey, M., Stacy, O. & Moely, B. (2000). "Approach" and "avoidance" coping and PTSD symptoms in innercity youth. *Current Psychology*, 19(1), 28-48.

Department of Health. (1999). *Caring About Carers: A National Strategy for Carers*. Stationery Office, London. Retrieved from https://www.gov.uk/government/news/a-national-strategy-for-carers

DeRoche, K. K., & Lahman, M. K. (2008, September). Methodological considerations for conducting qualitative interviews with youth receiving mental health services. *Forum Qualitative Sozialforschung/Forum: Qualitative Social Research,* 9(3), Art 17. Retrieved from http://nbn-resolving.de/urn:nbn:de:0114-fqs0803178

Docking, J. (2002). *Young Carers: The National Perspective-Statistics, Research and Good Practice***.** Report to the Rochdale Project Management Group Children's Fund – Young Carers. Great Britain: Social Services Department, Rochdale Metropolitan Borough Council.

Dodson, L., & Dickert, J. (2004). Girls' family labor in low-income households: A decade of qualitative research. *Journal of Marriage and Family*, 66(2), 318-332.

Driscoll, D. L., Appiah-Yeboah, A., Salib, P., & Rupert, D. J. (2007). Merging qualitative and quantitative data in mixed methods research: How to and why not. *Ecological and Environmental Anthropology*, 3(1), 19-28.

Duffy, A., Corman, J., & Pupo, N. (2015). Family Finances: Fragility, Class, and Gender. C*anadian Review of Sociology/Revue canadienne de sociologie*, 52(2), 222-231.

Dunlop, J. (2006). Privatization: how government promotes market based solutions to social problems. *Critical Social Work,* 7(2).

Duxbury, L. E., & Higgins, C. A. (2001). *Work-life balance in the new millennium: where are we?: where do we need to go?* (Vol. 4). Ottawa, ON: Canadian Policy Research Network.

Duxbury, L. E., & Higgins, C. A. (2012a). *Causes, Consequences, and Moderating Factors of Strain of Caregiving Among Employed Caregivers.* Ottawa, ON: Carleton University Sprott School of Business.

Duxbury, L., & Higgins, C. (2012b). *Revisiting work-life issues in Canada: The 2012 national* *study on balancing work and caregiving in Canada* [Report One]. Ottawa, ON: Carleton University Sprott School of Business.

Duxbury, L. E., Schroeder, B., & Higgins, C. A. (2009). *Balancing paid work and caregiving responsibilities: A closer look at family caregivers in Canada*. Ottawa, ON. Canadian Policy Research Networks.

Eakin, L. (2007). *We can't afford to do business this way: A study of the administrative burden resulting from funder accountability and compliance practices*. Toronto, ON: The Wellesley Institute.

Earley, L., & Cushway, D. (2002). The Parentified Child. *Clinical Child Psychology and Psychiatry*, 7(2), 163-178.

Earley, L., Cushway, D., & Cassidy, T. (2007). Children's perceptions and experiences of care giving: A focus group study. *Counselling psychology quarterly*, 20(1), 69-80.

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.

England, P., Budig, M., & Folbre, N. (2002). Wages of virtue: The relative pay of care work. *Social Problems*, 49(4), 455-473.

England, P., & Folbre, N. (1999). The cost of caring. *The Annals of the American Academy of Political and Social Science*, 561(1), 39-51.

Esteves, E. (2000). The New Wageless Worker: Volunteering and Market-Guided Health Care Reform. In Gustafson, D.L. (Ed.), *Care and Consequences. The Impact of Health Care Reform*. (pp. 154-176). Halifax, NS: Fernwood.

EDAC (Ethnic Disability Advocacy Centre) (2003). *Supporting CALD carers: the service*

Needs of culturally and linguistically diverse carers of people with disabilities. Perth: EDAC.

Esping-Anderson, G. (1990). *The Three Worlds of Welfare Capitalism.* Oxford: Princeton University Press.

Evans, B., Richmond, T., & Shields, J. (2005). Structuring Neoliberal Governance: The Nonprofit Sector, Emerging New Modes of Control and the Marketisation of Service Delivery. *Policy & Society,* 24(1), 73-97.

Farris-Manning, C., & Zandstra, M. (2003). *Children in care in Canada: A summary of current issues and trends with recommendations for future research.* Ottawa, ON: Child and Welfare League of Canada.

Fass, P.S. (2012). Viviana Zelizer: Giving Meaning to the History of Childhood. *The Journal of the History of Childhood and Youth,* 5(3), 457-461.

Ferguson, S. (2008). Canadian Contributions to Social Reproduction Feminism, Race and Embodied Labor. *Journalism,* Paper 4.

Folbre, N. (2006). Measuring care: Gender, empowerment, and the care economy. Journal of *Human Development*, 7(2), 183-199

Folbre, N. (2012). The Political Economy of Human Capital. *Review of Radical Political Economics*, 44(3), 281-292.

Foster, K. (2012, October). *Youth Employment and Un(der) employment in Canada.* Ottawa, ON: Canadian Centre for Policy Alternatives.

Frank, J. (1995) *Couldn't Care More: A Study of Young Carers and Their Needs.* London: The Children's Society.

Frank, J. (2002) *Making It Work: Good Practice with Young Carers and Their Families.*

London: The Children's Society and The Princess Royal Trust for Carers.

Frank, J. & McLarnon, J. (2007). *Key Principles of Practice for Young Carers, Parents and Their Families*. London: The Children's Society.

Fraser, M. (1997). *Risk and resilience in childhood: An ecological perspective.* Washington, DC: NASW Press.

Freeman, C. (2001). Is Local: Global as Feminine: Masculine? Rethinking the Gender of Globalization. *Signs,* 26(4), 1007-1038.

Freeman, J., King, M., & Pickett, W. (2016). *Health Behaviour in School-aged Children (HBSC) in Canada: Focus on relationships.* Public Health Agency of Canada: Ottawa, ON.

Fuller-Thomson, E. (2005). Canadian First Nations grandparents raising grandchildren: A portrait in resilience. *The International Journal of Aging and Human Development,* 60(4), 331-342.

Fullinwider-Bush, N., & Jacobvitz, D. B. (1993). The transition to young adulthood: Generational boundary dissolution and female identity development. *Family Process*, 32, 87-103.

Galarneau, D., Morissette, R. & Usalcas, J. (2016). *What has changed for young people in Canada?* Statistics Canada Catalogue No. 75-006-X. Ottawa, ON: Statistics Canada.

Gelinas, J. B. (2003). *Juggernaut Politics: Understanding Predatory Globalization*. New York, NY: Zed Books.

Gereffi, G., Humphrey, J., & Sturgeon, T. (2005). The governance of global value chains. *Review of international political economy*, 12(1), 78-104.

Gibson, K., O'Donnell, S., & Rideout, V. (2007). The project-funding regime: Complications for community organizations and their staff. *Canadian Public Administration*, *50*(3), 411-436.

Gignac, M.A.N., Kelloway, E.K. & Gottlieb, B.H. (1996). Impact of Caregiving on Employment: A Mediational Model of Work-Family Conflict. *Canadian Journal on Aging/La Revue Canadienne du Vieillissement*, 15(4), 525-542.

Giddens, A. (2013). *The third way: The renewal of social democracy*. Cambridge: John Wiley & Sons.

Gindin, S., Armstrong, H., Armstrong, P., Leys, C., Lister, J., Lexchin, J., & Mehra, N. (2005, December). *Whose health care? Challenging the corporate struggle to rule our system*. Toronto, ON: Socialist Project (Interventions Pamphlet Series).

Glaser, B. S., & Strauss, A. (1967). *The discovery of grounded theory*. New York, NY: Routledge.

Hammersley, M. A., & Atkinson, P. (1983): *Ethnography: principles in practice*. London: Tavistock Publications.

Gluck, S. B. (1987). *Rosie the riveter revisited: Women, the war, and social change*. Boston, MA: Twayne Publishers.

Government of Canada. (n.d). Benefits for caregivers. Ottawa, ON: Government of Canada. Retrieved from https://www.canada.ca/en/financial-consumer-agency/services/caring-someone-ill/benefits-tax-credits-caregivers.html

Government of Canada. (1882) Report of the Commissioners Appointed to Enquire into the Working of Mills and Factories in the Dominion, and the Labor Employed Therein" (Canada, Sessional Papers, 1882, IX No. 42). Ottawa, ON: Superintendent of printing.

Government of Canada. (1889). Report of the Royal Commission on the Relations of Labor and Capital in Canada. Ottawa, ON: Superintendent of printing. Retrieved from: http://publications.gc.ca/site/eng/472984/publication.html

Grant, K. R. (2004). *Caring for/caring about: Women, home care, and unpaid caregiving*. Toronto, ON: University of Toronto Press.

Grant, T., & McFarland, J. (2012, October 27). Generation Nixed: Why Canada's youth are losing hope for the future. *The Globe and Mail*. Retrieved from http://www.theglobeandmail.com/report-on-business/economy/jobs/generation-nixed-why-canadas-youth-are-losing-hope-for-the-future/article4705553/?page=all

Grant, T. (2014, November 4). Poloz's prescription for unemployed youth: Work for free. *The Globe and* Mail. Retrieved from http://www.theglobeandmail.com/report-on-business/economy/poloz-having-something-unpaid-on-your-cv-is-very-worth-it/article21439305/

Green, F. (2006). *Demanding work: The paradox of job quality in the affluent economy*. Princeton, NJ: Princeton University Press.

Green, D. A., & Sand, B. M. (2015). Has the Canadian labour market polarized? *Canadian Journal of Economics/Revue canadienne d'economique*, 48(2), 612-646.

Guba, E. G., & Lincoln, Y. S. (1982). Epistemological and methodological bases of naturalistic inquiry. *Educational Communication and Technology*, 30(4), 233-252.

Gullbrå, F., Smith-Sivertsen, T., Rortveit, G., Anderssen, N., & Hafting, M. (2014). To give the invisible child priority: Children as next of kin in general practice. *Scandinavian journal of primary health care*, 32(1), 17-23.

Gullestad, M. (1992). *The art of social relations: Essays on culture, social action and everyday* *life in modern Norway*. Oslo: Scandinavian University Press.

Haines, M.R. (1981). Poverty, Economic Stress, and the Family in a Late Nineteenth-Century American City: Whites in Philadelphia, I880. In T. Hershberg (Ed.), *Philadelphia: Work, Space, Family, and Group Experience in the Nineteenth Century* (pp. 240-276). New York, NY: Oxford University Press.

Hamilton, M. G., & Adamson, E. (2013). Bounded Agency in Young Carers' Lifecourse-stage Domains and Transitions. *Journal of Youth Studies,* 16(1), 101–117.

Harkness, J. A., Braun, M., Edwards, B., Johnson, T.P., Lyberg, L., Mohler, P.P., Pennell, B-E & Smith, T.W. (2010). *Survey Methods in Multinational, Multiregional, and Multicultural Contexts.* Hoboken, New Jersey, NJ: Wiley.

Harris, M., & Manning, P. (2007). *Vision for a Canada Strong and Free* (Vol. 6). Vancouver, BC: The Fraser Institute.

Hartinger-Saunders, R.M. (2008). The history of defining youth: Current implications for identifying and treating delinquent youth. *The New York Sociologist*, 3, 88-90.

Harvey, D. (2011). *The enigma of capital: and the crises of capitalism*. New York, NY: Profile Books.

Henderson, A., Brown, S. D., Pancer, S. M., & Ellis-Hale, K. (2007). Mandated community service in high school and subsequent civic engagement: The case of the "double cohort" in Ontario, Canada. *Journal of Youth and Adolescence*, 36(7), 849-860.

Herman-Stabl, M.A., Stemmler, M. & Petersen, A.C. (1995). Approach and avoidant coping: Implications for adolescent mental health. *Journal of Youth Adolescence*, 24(6), 649-665.

Hill, T., Smyth, C., Thomson, C., & Cass, B. (2009). *Young carers: their characteristics and* *geographic distribution: report to the National Youth Affairs Research Scheme*. Canberra: National Youth Affairs Research Scheme (NYARS).

Hillier, S. L., Civetta, L., & Pridham, L. (2010). A systematic review of collaborative models for health and education professionals working in school settings and implications for training. *Education for Health*, 23(3), 393.

Hindman, H. D. (2009). *The world of child labor: An historical and regional survey*. New York, NY: M.E. Sharpe Inc.

HM Government. (2008). *Carers at the Heart of 21st – Century Families and Communities.* London: Department of Health.

Hobbs, S., McKechnie, J., & Lavalette, M. (1999). *Child labor: A world history companion*. Santa Barbara, CA: ABC-CLIO.

Hochschild, A., & Machung, A. (1989, 2003, 2012). *The second shift: Working families and the revolution at home*. New York, NY: Penguin.

Hodkinson, P. & Deicke, W. (2007). *Youth cultures: Scenes, subcultures and tribes*. New York: Routledge.

Hospice Toronto. (2015, February 6). *Mission and Goals.* Retrieved from http://www.ycptoronto.com/

House of Commons Canada. (February, 2011). C*hanging the Long-Form Census—Its Impact on Women's Equality in Canada: Report on the Standing Committee on the Status of Women*. Meeting No 55, 40th Parliament, 3rd session. Retrieved from http://www.ourcommons.ca/DocumentViewer/en/40-3/FEWO/report-10/

Huber, J. (1976). Toward a sociotechnological theory of the women's movement. *Social Problems*, 23(4), 371-88.

Hunt, E., & McKay, E. A. (2015). What can be learned from adolescent time diary research. *Journal of Adolescent Health*, 56(3), 259-266.

Hurl, L. F. (1988). Restricting child factory labour in late nineteenth century Ontario. *Labour/Le Travail*, 21, 87-121.

Huws, U., & Dahlmann, S. (2010). Global Restructuring of Value Chains and Class Issues. In N. Pupo & M. Thomas, (Eds.), Interrogating the new economy: Restructuring work in the 21st century (65-92). Toronto, ON: University of Toronto Press.

Imagine Canada. (2006). *National Survey of Nonprofit and Voluntary Organizations: Financial Challenges of Nonprofit and Voluntary Organizations*. Toronto, ON: Imagine Canada. Retrieved from http://www.imaginecanada.ca/sites/default/files/www/en/nsnvo/d_ontario_sector_report.pdf

ILO (International Labour Organization). (2013). *Global Employment Trends for Youth 2013.* Geneva: ILO. Retrieved from http://www.ilo.org/wcmsp5/groups/public/@dgreports/@dcomm/documents/publication/wcms_212423.pdf

Jacobvitz, D. B., & Bush, N. F. (1996). Reconstructions of family relationships: Parent-child alliances, personal distress, and *self-esteem. Developmental Psychology, 32, 732–743.*

James, A., & Prout, A. (Eds.). (2015). *Constructing and reconstructing childhood: Contemporary issues in the sociological study of childhood*. Abingdon, OX: Routledge.

Jansen, I. (October 2009). Residential Long-Term Care in Canada: Our Vision for Better Seniors' Care. Ottawa, ON: *Canadian Union of Public Employees*.

Jenkins, S., & Wingate, C. (1994). Who cares for young carers? *British Medical Journal,* 308(6931), 733-734.

Johnston, J. R., Gonzàlez, R., & Campbell, L. E. (1987). Ongoing postdivorce conflict and child disturbance. *Journal of Abnormal Child Psychology*, 15(4), 493-509.

Joseph, S., F. Becker, & Becker, S. (2009). *Manual for Measures of Caring Activities and Outcome for Children and Young People*. Essex: The Princess Royal Trust for Carers.

Larbi, G. (1999). *The new public management approach and crisis states.* Vol. 112, Discussion Paper. Geneva: United Nations Research Institute Social Development.

Lopetegui, M., Yen, P. Y., Lai, A., Jeffries, J., Embi, P., & Payne, P. (2014). Time motion studies in healthcare: what are we talking about?. *Journal of biomedical informatics*, 49, 292-299.

Luthar, S. S. (Ed.). (2003). *Resilience and vulnerability: Adaptation in the context of childhood adversities*. Cambridge, MA: Cambridge University Press.

Luthar, S. S., Cicchetti, D., & Becker, B. (2000). The Construct of Resilience: A Critical Evaluation and Guidelines for Future Work. *Child Development*, 71(3), 543-562.

Luxton, M. & Vosko, L. F. (1998). Where Women's Efforts Count: The 1996 Census Campaign and 'Family Politics' in Canada. *Studies in Political Economy*, 56, 49-89.

Kallander, E. K., Weimand, B. M., Becker, S., Van Roy, B., Hanssen-Bauer, K., Stavnes, K., Faugli, A., Kufas, E., & Ruud, T. (2017). Children with ill parents: extent and nature of caring activities. *Scandinavian Journal of Caring Sciences*. Doi: 10.1111/scs.12510.

Kärkkäinen, R., Räty, H., & Kasanen, K. (2009). Parents' perceptions of their child's resilience and competencies. *European Journal of Psychology of Education,* 24 (3), 405-419.

Katz, M. B., & Stern, M. J. (2006). *One nation divisible: What America was and what it is becoming*. New York, NY: Russell Sage Foundation.

Kaufman, J., & Charney, D. (2000). Comorbidity of mood and anxiety disorders. *Depression and anxiety*, 12(s1), 69-76.

Kavanaugh, M. S., Stamatopoulos, V., Cohen, D., & Zhang, L. (2015). Unacknowledged Caregivers: A Scoping Review of Research on Caregiving Youth in the United States. *Adolescent Research Review*, 1-21.

Keith, L., & Morris, J. (1995). Easy targets: A disability rights perspective on the 'children as carers' debate. *Critical Social Policy,* 15, 36–57.

Klein, S., & Montgomery, B. (2001). *Depressing Wages. Why welfare cuts hurt both the welfare and working poor*. Ottawa, ON: Canadian Centre for Policy Alternatives.

Kohli, M. (2003). *The golden bridge: Young immigrants to Canada, 1833-1939*. Toronto, ON: Natural Heritage Inc.

Kraus, A. (2015). *Scholarly Principles in Teacher Education: What Kind of Science Serves a Practice-Oriented Teacher Education*? New York, NY: Waxmann.

Kuhn, P. (1996, December). *Labour Market Polarization: Canada in International Perspective*. Paper presented for the fourth annual Bell Canada Papers Conference. London, ON.

Lacovetta, F., Quinlan, M., & Radforth, I. (1996). Immigration and labour: Australia and Canada compared. *Labour History*, 71, 90-115.

Lareau, A. (2003). *Unequal childhoods: Race, class and family life*. Berkeley, CA: University of California Press.

Lee, S., Brick, J. M., Brown, E. R., & Grant, D. (2010). Growing cell-phone population and noncoverage bias in traditional random digit dial telephone health surveys. *Health services research*, 45(4), 1121-1139.

Lestary, S. (2013, December 19). *How Globalization Impacts the Institution Of The Family. Global Peace Foundation*. Washington, DC: Global Peace Foundation. Retrieved from https://www.globalpeace.org/news/how-globalization-impacts-institution-family

Leu, A., & Becker, S. (2017). A cross-national and comparative classification of in-country awareness and policy responses to 'young carers'. *Journal of Youth Studies*, 20(6), 750-762.

London House of Commons. Work and Pensions Committee. (2008). *Valuing and Supporting Carers: Fourth Report of Session, 2007-08*. (Vol 1). London: The Stationery Office.

Lowe, G. (2006). *Under pressure: Implications of work-life balance and job stress*. Kingston, ON: Wilson Banwell PROACT Human Solutions.

Lowe, G. S., & Schellenberg, G. (2001). *What's a Good Job? The Importance of Employment Relationships.* CPRN Study No. W|05. Ottawa, ON: Canadian Policy Research Networks.

Lasch, C. (1979). Haven in a Heartless World The Family Besieged. J*uvenile and Family Court Journal*, 30(4), 59-60.

Lessard, C., & Brassard, A. (2009). Education governance in Canada, 1990-2003: Trends and significance. In C. Levine-Rasky (Ed.), *Canadian perspectives on the sociology of education* (pp. 255-274). Toronto, ON: Oxford University Press.

Luke, H. (2004). *Who's Looking Out for Our Kids? Deregulating Child Labour Law in BC*. Ottawa, ON: Canadian Centre for Policy Alternatives.

Lum, J. (July, 2008). *In Focus: Informal Caregiving.* Toronto, ON: Canadian research network for care in the community (CRNCC).

Lusardi, A., D. Schneider & Tufano, P. (2011). Financially Fragile Households: Evidence and

Implications. *Brookings Papers on Economic Activity,* (1), 83-134.

Luxton, M. (1980). *More than a labour of love: Three generations of women's work in the home* (with 2009 Preface). Toronto, ON: Women’s Press.

Luxton, M. (1981). Taking on the Double Day: Housewives as a Reserve Army of Labour. *Atlantis,* 7(1), 12-32.

Luxton, M., & Corman, J. (1991). Getting to Work: The Challenge of the 'Women Back Into Stelco' Campaign. *Labour/Le Travail*, 28, 149-85.

Luxton, M., & Fox, B. (2009). Conceptualizing family. In B. Fox (Ed.). *Family Patterns and Gender Bonds* (pp 3-20). Toronto, ON: Oxford University Press.

MacSween, L., & Maule, D. (2012). Young Carers' Movement in Toronto. *Relational Child and Youth Care Practice*, 25(2), 61.

Makwarimba, E. (2006). Immigrant women family caregivers in Canada: Implications for policies and programmes in health and social sectors. *Health and Social Care in the Community,* 24(4), 329-340.

Mandell, N., & Stamatopoulos, V. (2017). Support and Support for Older Persons. In A. Gaszo & K. Koboyashi (Eds.), C*ontinuity and Change: Canadian Families in the New Millennium* (pp.199-215). Toronto, ON: Nelson Education Ltd.

Marshall, K. (2006). Converging gender roles. *Perspectives on labour and income*, 18(3), 7.

Marshall, K. (2011, Winter). *Generational change in paid and unpaid work.* Canadian Social Trends Catalogue No. 11-008-X. Ottawa, ON: Statistics Canada.

Masten, A. S. & Powell, J. L. (2003) A resilience framework for research, policy, and practice. In S. S. Luthar (Ed.), *Resilience and vulnerability: Adaptation in the context of childhood adversities* (pp. 1–28). New York, NY: Cambridge University Press.

McCloud, L. & Dwyer, R. (2011). The Fragile American: Hardship and Financial Troubles in the 21st Century. *The Sociological Quarterly,* 52(1), 13-35.

McDonald's (April 8, 2013). Newsroom: McDonald's Set to Serve Up More Than 6,000 Jobs in Canada on National Hiring Day. Retrieved from http://news.mcdonalds.ca/en-CA/manual-releases/McDonald-s-Set-to-Serve-Up-More-Than-6,000-Jobs-in

Margolis, R., & Iciaszczyk, N. (2015). The changing health of Canadian grandparents. *Canadian Studies in Population*, 42(3-4), 63-76.

Margolis, R., & Wright, L. (2017). Healthy Grandparenthood: How long is it and how has it changed? *Demography*. DOI 10.1007/s13524-017-0620-0

Marx, K. (1887). *Capital: a critical analysis of capitalist production*. Moscow: Progress Publishers.

Matthews, S. H. (1995). Gender and the division of filial responsibility between lone sisters and their brothers. *Journal of Gerontology: SOCIAL SCIENCES,* 50B, S312–S320.

Mawhinney, H. B. (1994). The policy and practice of community enrichment of schools. *Proceedings of the Education and Community Conference, Department of Educational Administration.* Toronto, ON: Ontario Institute for Studies in Educational Administration.

Mays, G. L. & Winfree, L. T. (2000). Juvenile Justice. Boston, MA: McGraw Hill.

Meredith, H. (1991). Young Carers: the Unacceptable Face of Community Care. *Social Work and Social Sciences Review*, 3, 47–51.

Meredith, H. (1992). Supporting the Young Carer. *Community Outlook*, May 2(5), 15-18.

Mies, M. (1986). *Patriarchy and Accumulation on a World Scale*. London: Zed Books.

Milan, A., & Hamm, B. (2003). *Across the generations: Grandparents and grandchildren.* Canadian Social Trends Catalogue No. 11-008-XIE. Ottawa, ON: Statistics Canada.

Milan, A., L. A. Keownm, & Covadonga, R.U. (2011). *Families, Living Arrangements and Unpaid Work (*Chapter in Women in Canada: A Gender based Statistical Report). Statistics Canada Catalogue No. 89–503-X. Ottawa, ON: Statistics Canada.

Mills, C. W. (1959). *The sociological imagination*. New York, NY: Oxford University Press.

Minge-Kalman, W. (1978). The industrial revolution and the European family: the institutionalization of 'childhood' as a market for family labor. *Comparative Studies in Society and History*, 20(3), 454-468.

Minuchin, S., Montalvo, B., Guerney, B.G., Rosman, B., & Schumer, F. (1967). *Families of the slums.* New York, NY: Basic Books.

Mintz, S. (2004*). Huck's raft: A history of American childhood*. Cambridge, MA: Harvard University Press.

Misic, A. (1996). *The hidden society: a study of non-English speaking background carer issues in the western Sydney region*. Sydney: The Carers Association of NSW.

Moore, T. (2005a). *Reading between the lines: The experiences of children and young people about their experiences of young caring in the ACT*. Lyneham: Youth Coalition of the ACT.

Moore, T. (2005b). Young carers and education. Identifying the barriers to satisfactory education for young carers. *Youth Studies Australia*, 24(4), 50−55.

Moore, T. (2005c). *More than words: Supporting young carers and their families*. Lyneham: Youth Coalition of the ACT.

Moore, T., & McArthur, M. (2007). We're all in it together: Supporting young carers and their families in Australia. *Health and Social Care in the Community*, 15(6), 561-568.

Moos RH. (1990). *Coping Response Inventory – Youth Form, preliminary manual.* Palo Alto, CA: Stanford University Medical Center.

Morissette & Galarneau (2016). *Labour Market Participation of Immigrant and Canadian-born Wives, 2006 to 2014*. Statistics Canada Catalogue no. 11-626-X - No. 055. Ottawa, ON: Statistica Canada.

Morris, J. (1997). A response to Aldridge & Becker—disability rights and the denial of young carers: the dangers of zero-sum arguments. *Critical Social Policy*, 17(51), 133-135.

Morse, J.M. (2003). Principles of mixed methods and multimethod research design. In A, Tashakkori & C. Teddie (Eds.). *Handbook of mixed methods in social & behavioural research* (pp. 189-208). Thousand Oaks, CA: Sage.

Murphy, B. (2004, November). *Towards a feminist political economy*. Inter Pares Occasional Paper No. 5. Ottawa, ON: Inter Pares.

National Alliance for Caregiving/United Hospital Fund. (2005). *Young caregivers in the U.S.: Report of findings*. Bethesda, MD: National Alliance for Caregiving.

National Health Service. (2015). *Carers' rights and the Care Act*. London: NHS Information Centre. Retrieved from http://www.nhs.uk/conditions/social-care-and-support-guide/pages/carers-rights-care-act-2014.aspx

National Crime Prevention Centre. (2009). *School-Based Drug Abuse Prevention: Promising and Successful Programs*. Ottawa, ON: Public Safety Canada.

National Union Research. (May, 2000). *Workfare: A Low wage strategy for the Canadian economy*. Nepean, Ontario: National Union of Public and General Employees.

Nelson, A. L. (2005). *Safe patient handling and movement: A practical guide for health care professionals*. New York, NY: Springer Publishing Company.

Newman, T. (2002). Young Carers and Disabled Parents: Time for a Change of Direction? *Disability and Society* 17(6): 613–25.

Nichols, K. R., Fam, D., Cook, C., Pearce, M., Elliot, G., Baago, S. & Chow, T. W. (2013). When dementia is in the house: needs assessment survey for young caregivers. *The Canadian Journal of Neurological Sciences,* 40(1), 21-28.

Occupational Health Clinics for Ontario Workers (OHCOW). (N.D.). Patient Handling for Healthcare Workers. Hamilton, ON: OHCOW. Retrieved from: http://www.ohcow.on.ca/uploads/Resource/General%20Handouts/Healthcare%20Workers%20Patient%20Handling.pdf

Office for National Statistics. (2011). *2011 Census Questions*. London: Office for National Statistics.

Office for National Statistics. (2013). *Providing Unpaid Care May Have an Adverse Affect on Young Carers' General Health*. London: Office for National Statistics.

Ofsted. (2013, March). *Reducing Young caring through family group conferencing – Bolton Council and Barnardo's*. Manchester: Ofsted.

Olsen, R. (2000). Families under the Microscope: Parallels between the Young Carers Debate of the 1990s and the Transformation of Childhood in the Late Nineteenth Century. *Children & society,* 14(5), 384-394.

Olsen, R. (1996). Young Carers: Challenging the Facts and Politics of Research into Children and Caring, *Disability and Society*, 11(1): 41–5.

Olsen, R. (1999). Young carers and the `disability' response: identifying common ground', *Journal of Young Carers Work*, 2, 4-7.

Olsen, R. & Parker, G. (1997). A Response to Aldridge and Becker – 'Disability Rights and the

Denial of Young Carers: The Dangers of Zero-Sum Arguments'. *Critical Social Policy*, 50: 125-33.

Ontario Committee on Child Labour. (1907). *Report on Child Labour, 1907*. Journals of the Legislative Assembly of Ontario, Vol 41. Toronto, ON: Kings Printer.

Ontario Health Coalition. (2016, January 31). *Submission to the Standing Committee on Finance & Economic Affairs*. Toronto, ON: Ontario Health Coalition. Retrieved from http://www.ontariohealthcoalition.ca/wp-content/uploads/final-submission-11.pdf

Ottawa Network for Education. (2016). Substance Abuse and Youth in School Coalition. Ottawa, ON: Ottawa Network for Education.

Pakenham, K., & Bursnall, S. (2006). Relations between social support, appraisal and coping and both positive and negative outcomes for children of a parent with multiple sclerosis and comparisons with children of healthy parents. *Clinical Rehabilitation*, 709-723.

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.

Palys, T. (2008). Purposive sampling. In L. Given (Ed.). *The sage encyclopedia of qualitative research methods* (pp. 57–59). Thousand Oaks, CA: Sage.

Panitch, L., & Swartz, D. (2008). *From consent to coercion: The assault on trade union freedoms*. Toronto, ON: University of Toronto Press.

Parker, R. (2010). *Uprooted: The shipment of poor children to Canada, 1867-1917*. Vancouver, BC: UBC Press.

Parker, L. E., Kirchner, J. E., Bonner, L. M., Fickel, J. J., Ritchie, M. J., Simons, C. E., & Yano,

E. M. (2009). Creating a quality-improvement dialogue: utilizing knowledge from frontline staff, managers, and experts to foster health care quality improvement. *Qualitative Health Research*, 19, 229–242.

Parr, J. (1980). *Labouring children: British immigrant apprentices to Canada, 1869-1924.* Montreal, QC: McGill-Queen's Press-MQUP.

Parsons, T. (1942). Age and sex in the social structure of the United States. *American sociological review*, 604-616.

ParticipACTION (2016). *Are Canadian kids too tired to move? The 2016 ParticipACTION Report Card on Physical Activity for Children and Youth*. Toronto, ON: ParticipACTION.

Phillips, S., & Levasseur, K. (2004). The Snakes and Ladders of Accountability: Contradictions between contracting and collaboration for Canada's voluntary sector. *Canadian Public Administration*, 47(4), 451-474.

Phillips, R.F. (2010). Initiatives to support disadvantaged young people: enhancing social capital and acknowledging personal capital. *Journal of youth studies*, 13(4), 489-504.

Postman, N. (1982). *The disappearance of childhood*. New York, NY: Vintage Books.

Pupo, N., & Duffy, A. (2012). Unpaid work, capital and coercion. *Work Organization, Labour and Globalization*, 6(1), 27-47.

Pupo, N., & Thomas, M. P. (Eds.). (2010). *Interrogating the new economy: Restructuring work in the 21st century. Toronto*, ON: University of Toronto Press.

Purcal, C., Hamilton, M., Thomson, C., & Cass, B. (2012). From assistance to prevention: categorizing young carer support services in Australia, and international implications. *Social policy & administration,* 46(7), 788-806.

Qvortrup, J. (1993). Societal position of childhood: The international project childhood as a social phenomenon. *Childhood,* 1(2), 119-124.

Qvortrup, J. (1999). *Childhood and Societal Macrostructures: Childhood Exclusion by Default. Working Paper No. 9*, Odense, DK: Odense University Department of Contemporary Cultural Studies.

Qvortrup, J. (2001). School-work, paid work and the changing obligations of childhood. In P. Mizen, C.J. Pole & A. Bolton (Eds.), *Hidden Hands: International Perspectives on Children's Work and Labour* (pp. 91-108). London: RoutledgeFalmer.

Regoli, R. M. & Hewitt, J. D. (1997). *Delinquency in Society*. Boston, MA: McGraw Hill.

Rende, R. (2015). *The misperception of chores: What's really at stake?* Benton Harbour, MI: Whirlpool Corporation.

Rende, R., & Prosek, J. (2015). *Raising can-do kids: Giving children the tools to thrive in a fast-changing world*. New York, NY: Penguin.

Rennie, S. (2013, September 11). National Household Survey: Immigrants, minorities struggle in Canada. *The Toronto Star*. Retrieved from https://www.thestar.com/news/canada/2013/09/11/national_household_survey_immigrants_minorities_struggle_in_canada.html

Richards, L., & Richards, T. (1991). Computing and qualitative analysis: computational paradigms and research processes'. In N.G. Fielding & R.M Lee (Eds.), *Using Computers in Qualitative Research* (pp. 445-462). London: Sage.

Richmond, T., & Shields, J. (2004). NGO restructuring: Constraints and consequences. *Canadian Review of Social Policy*, 53, 53-67.

Roberts, G. (2012*). Analyzing Census microdata in an RDC: What weight to use?.* The Research

Data Centres Information and Technical Bulletin. Catalogue No. 12-002-X. Ottawa, ON: Statistics Canada.

Roche, J., & Tucker, S. (2003). Extending the Social Exclusion Debate: An Exploration of the Family Lives of Young Carers and Young People with ME. *Childhood,* 10 (4), 439–456.

Romano, M.D. (1976) Preparing children for parental disability. *Social Work in Health Care*, 1(3), 309–315.

Rose, H.D. & Cohen, K. (2010). The experiences of young carers: a meta-synthesis of qualitative findings. *Journal of youth studies*, 13(4), 473-487.

Rossmann, M. (2003, Winter). *Getting Children Involved in Household Tasks: Is It Worth the Effort? Minnesota Council on Family Relations Forum*, 5. Retrieved from https://mn.ncfr.org/wp-content/uploads/sites/3/2014/02/2003_winter.pdf

Sagan, A. (2015, October 1). High school volunteering: As some struggle to secure hours, others raise bar. CBC News. Retrieved from: http://www.cbc.ca/news/canada/high-school-volunteering-as-some-struggle-to-secure-hours-others-raise-bar-1.3201991

Saldana, J. (2009). *The Coding Manual for Qualitative Researchers.* New York, NY: Sage.

Salter, J. (1999). *The Health Needs of Young Carers: A pilot study*. London: The Children's Society.

Sattler, P. (2012). Education Governance Reform in Ontario: Neoliberalism in Context. *Canadian Journal of Educational Administration and Policy*, 1-28.

Sassen, S. (1998). *Globalization and its discontents: Essays on the New Mobility of People and Money*. New York, NY: The New Press.

Scoffield, H. (2010, July 28). Voluntary census deletes questions about unpaid work. *The Globe & Mail.* Retrieved from http://www.theglobeandmail.com/news/politics/voluntary-census-deletes-questions-about-unpaid-work/article1389740/

Schellenberg, G., Turcotte, M., & Ram, B. (2005). *Post-retirement employment*. Statistics Canada Catalogue no. 75-001-XIE. Ottawa, ON: Statistics Canada.

Schlarmann, J. G., Metzing-Blau, S., & Schnepp, W. (2011). Implementing and evaluating the first German young-carers project: Intentions, pitfalls and the need for piloting complex interventions. *The Open Nursing Journal*, 5, 38.

Seccombe, W. (1987). Reflections on the domestic labor debate and prospects for Marxist-feminist synthesis. In R. Hamilton & M. Barrett (Eds.), *The politics of diversity: Feminism, Marxism and nationalism* (pp. 190-297). Montreal, ON: Book Centre Inc.

Seccombe, K. (2002). "Beating the odds" versus "Changing the odds": Poverty, resilience, and family policy. *Journal of Marriage and Family,* 64(2), 384–394

Segal, J. & Simpkins, J. (1993). *My mum needs me: helping children with ill or disabled parents.* Harmondsworth: Penguin.

Senn, M. J. (1975). Insights on the child development movement in the United States. *Monographs of the Society for Research in Child Development,* 161(40), 1-107.

Shalla, V. (2011). *Working in a Global Era: Canadian Perspectives*. Toronto, ON: Canadian Scholars' Press.

Sharma, N. R. (2006). *Home economics: Nationalism and the making of 'migrant workers' in Canada.* Toronto, ON: University of Toronto Press.

Silversides, A. (2011). *Long-Term Care in Canada: Status Quo No Option.* Ottawa, ON: The Canadian Federation of Nurses Union.

Simeone, T. (2008). *The arctic: Northern aboriginal peoples.* Ottawa, ON: Library of

Parliament. Retrieved from http://www.lop.parl.gc.ca/content/lop/researchpublications/prb0810-e.html

Sinha, M. (2013). *Portrait of Caregivers, 2012*. Statistics Canada Catalogue No. 89-652-X. Ottawa, ON: Statistics Canada.

Skovdal, M., Ogutu, V., Aoro, C., & Campbel, C. (2009). Young carers as social actors: Coping strategies of children caring for ailing or ageing guardians in Western Kenya. *Social Science & Medicine*, 69, 587-595.

Skovdal, M., & Daniel, M. (2012). Resilience through participation and coping-enabling social environments: the case of HIV-affected children in sub-Saharan Africa. *African journal of AIDS research*, 11(3), 153-164.

Smith, T. W. (2010). The Globalization of Survey Research. In J. Harkness, M. Braun, B. Edwards, T. P. Johnson, L. Lyberg, Peter Ph. Mohler, B.-E. Pennell, and T. W. Smith (Eds.), *Survey Methods in Multinational, Multiregional, and Multicultural Contexts* (pp. 477–484). New Jersey, NJ: Wiley.

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.

Spitze, G., & Logan, J. (1990). Sons, daughters, and intergenerational social support. *Journal of Marriage and the Family*, 52, 420–430.

Social Exclusion Task Force (2008). *Think Family: Improving the life chances of families at risk,* London: Cabinet Office.

Song, M. (1999). *Helping Out: Children's Labor in Ethnic Businesses*, Philadelphia, PA: Temple University Press.

Spitzer, D. (2004). Invisible Bodies: Minority, Women, Nurses, Time and the New Economy of Care. *Medical Anthropology Quarterly,* 18(4), 490-508.

Stewart, M., Nuefeld, A., Harrison, M., Spitzer, D., Hughes, K., & Makwarimba, E. (2006). Immigrant women family caregivers in Canada: Implications for policies and programmes in health and social sectors. *Health and Social Care in the Community*, 24(4), 329-340.

Standing, G. (1999). Global Feminization through Flexible Labour: A Theme Revisited. *World Development,* 27(3), 583-602.

Stalker, G., & Ornstein, M. (2013). Quebec, daycare, and the household strategies of couples with young children. *Canadian Public Policy*, 39(2), 241-262.

Stamatopoulos, V. (2015). One million and counting: The hidden army of young carers in Canada. *Journal of Youth Studies,* 18(6), 809-822.

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.

Standing, G. (2011). *The Precariat: The New Dangerous Class*. London: Bloomsbury Academic.

Statistics Canada. (1996). *Census of Canada, 1996, Families File* (Public-use Microdata File). Statistics Canada (Producer). Using ODESI (Distributor). Retrieved from http://researchguides.library.yorku.ca/census

Statistics Canada. (2006a). *Census of Canada, 2006, Families File* [Data file, code book and user guide]. Statistics Canada (Producer). Using ODESI (Distributor). Retrieved from http://researchguides.library.yorku.ca/census.

Statistics Canada. (2006b). *Long Form Census Questionnaire.* Ottawa, ON: Statistics Canada.

Statistics Canada. (2011). *Women in Canada: A Gender-based Statistical Report*. Statistics

Canada Catalogue No. 89-503-X. Ottawa, ON: Statistics Canada.

Statistics Canada. (2012a). *Fifty years of families in Canada: 1961 to 2011*. Statistics Canada Catalogue No. 98-312-X2011003. Ottawa, ON: Statistics Canada.

Statistics Canada. (2012b). *General social survey (GSS), 2012, cycle 26, Caregiving and Care Receiving (main file)* [Data file, code book and user guide]. Using ODESI (Distributor). Retrieved from http://search1.odesi.ca.ezproxy.library.yorku.ca

Statistics Canada. (2013a). *Immigration and Ethnocultural Diversity in Canada*. Statistics Canada Catalogue No. 99-010-X2011001. Ottawa, ON: Statistics Canada.

Statistics Canada. (2013b). *Residential Telephone Service Survey, 2013.* The Daily. Statistics Canada Catalogue no. 11-001-X. Ottawa, ON: Statistics Canada.

Statistics Canada. (2013c). *General Social Survey: An Overview, 2013.* Statistics Canada Catalogue no. 89F0115X. Ottawa, ON: Statistics Canada.

Statistics Canada. (2015a). Income of Canadians, 2000 to 2013. *The Daily.* December 17. Statistics Canada catalogue no. 11-001-X. Ottawa, ON: Statistics Canada.

Statistics Canada. (2015b). *Study: Grandparents living with their grandchildren, 2011*. Statistics Canada catalogue no. 11-001-X. Ottawa, ON: Statistics Canada.

Stearns, P. N. (2010). *Childhood in world history*. Oxon, UK: Routledge.

Stearns, P.N. (2016). *The Industrial Turn in World History.* New York, NY: Taylor & Francis.

Stinson, J. (2004). Why privatization is a women's issue. *Canadian Woman Studies*, 23(3/4), 18.

Struthers, M. (2013, June). *Fair Exchange: Public funding for social impact through non-profit sector*. Toronto, ON: Metcalf Foundation.

Sun-Hee Park, L. (2002). Asian Immigrant Entrepreneurial Children. In L.T Vo & R. Bonus

(Eds.). Contemporary Asian American Communities: Intersections and Divergences (pp. 161-174). Philadelphia, PA: Temple University Press.

Tannock, S. (2001). *Youth at work: The unionized fast-food and grocery workplace*. Philadelphia, PA: Temple University Press.

Teddie, C., & Tashakkori, A. (2003). Major issues and controversies in the use of mixed methods in the social and behavioural sciences. In A, Tashakkori & C. Teddie (Eds.). *Handbook of mixed methods in social & behavioural research* (pp. 3-50). Thousand Oaks, CA: Sage.

Tiessen, K. (2015, April 10). *Making Ends Meet Toronto's 2015 Living Wage*. Ottawa, ON: Canadian Centre for Policy Alternatives.

Thomas, M. (2004). Setting the minimum: Ontario's employment standards in the postwar years, 1944-1968. *Labour/Le Travail,* 49-82.

Thomas, N., Stainton, T., Jackson, S., Cheung, W.Y., Doubtfire., S & Webb, A. (2003). Your friends don't understand: invisibility and unmet need in the lives of young carers, *Child and Family Social Work*, 8, 35–46.

Thorne, B, (2012). Pricing the Priceless Child as a Teaching Resource. *The Journal of the History of Childhood and Youth,* 5(3), 474-480.

Thrasher, F. (1927). The Gang: A Study of 1313 Gangs in Chicago. Chicago: University of Chicago Press.

Toporas, C. (May, 2003). *Growing up strong: Supporting the children of parents with Multiple sclerosis.* Toronto, ON: MS Society of Canada.

Tourangeau, R., L. J. Rips, and K. Rasinski. (2000). *The Psychology of Survey Response.* Cambridge, MA: Cambridge University Press.

Toronto District School Board. (Spring 2009). *Absenteeism in the TDSB.* Research Today*,* 4(1), 1-2. Retrieved from http://www.tdsb.on.ca/Portals/research/docs/reports/RT_Absenteeism.pdf

Toronto District School Board (2013). *2011-2012 Student Census*. Retrieved from http://www.tdsb.on.ca/Portals/research/docs/reports/2011StudentCensus.pdf

Toronto District School Board. (2016). *2015-2016 TDSB Board Improvement Plan for Student Achievement K-Grade 12+*. Retrieved from http://www.tdsb.on.ca/Portals/0/AboutUs/Accountability/BIPSA%202015-16.pdf

Tucker, S. & Liddiard, P. (1999) Young carers, in: A. Brechin, J. Walmsley, J. Katz & S. Peace (Eds). *Care matters: concepts, practice and research in health and social care* (pp. 54-65). London: Sage.

Turcotte, M. (2014). *Canadians with unmet home care needs.* Statistics Canada Catalogue No. 75-006-X. Ottawa, ON: Statistics Canada.

Valleau, P.M., Raymond, M.B., & Horton, C.B. (1995). Parentification and caretaker syndrome: An empirical investigation. *Family Therapy,* 22(3), 157-164.

Van Eyck, K. (2003). Flexibilizing Employment: An Overview. International Labour Office: Geneva.

Vedel, I., Monette, M., Beland, F., Monette, J., & Bergman, H. (2011). Ten years of integrated care: backwards and forwards. The case of the province of Québec, Canada. *International journal of integrated care*, 11(5), 1-11.

Vezina, M & Crompton. S. (2012). *Volunteering in Canada.* Statistics Canada Catalogue No. 11-008-X. Ottawa, ON: Statistics Canada.

Volunteer Canada. (n.d). *Engaging Volunteers: Youth*. Ottawa, ON: Volunteer Canada.

Retrieved from
http://volunteer.ca/youth

Vosko, L. F. (2000). *Temporary work: The gendered rise of a precarious employment relationship*. Toronto, ON: University of Toronto Press.

Vosko, L. F. (2006). *Precarious employment: Understanding labour market insecurity in Canada.* Montreal, QC: McGill-Queen's Press-MQUP.

Yans-McLaughlin, V. (1977). *Family and community: Italian immigrants in Buffalo, 1880-1930.* New York, NY: Cornel University Press.

Ungerleider, C., & Levin, B. (2007). Accountability, funding and school improvement in Canada. In T. Townsend (Ed.), *International handbook of school effectiveness and improvement* (pp. 411-424). Dordrecht: Springer.

Ungar, M. (2008). Resilience across Cultures. *British Journal of Social Work,* 38, 218-235.

Ursel, Jane. (1992). *Private Lives, public policy: 100 years of state intervention in the family*. Toronto, ON: Women's Press.

Walker, A. J., Pratt, C. C., & Eddy, L. (1995). Informal caregiving to aging family members: A critical review. *Family Relations*, 44, 402-411.

Walks, A. (2013). *Canada Growing Unequal: The Evidence & the Need for Labour Market & Tax Reform*. Toronto, ON: Neighbourhood Change Research Partnership.

Wates, M. (2003). *It shouldn't be down to luck: Results of a consultation with disabled parents.* London: Disabled Parents Network

Ward-Griffin, C., Brown, J., McNair, S., & Vandervoort, A. (2005). Double-Duty Caregiving: Women in the Health Professions. *Canadian Journal on Aging*, 24(4), 379-394.

Waugh, E., Szafran, O., Duerksen, K., Torti, J., Charles, G., & Shankar, J. (2015). Is there a care gap for young carers in Canada? Edmonton community agencies' perspectives. *Canadian Journal of Family and Youth/Le Journal Canadien de Famille et de la Jeunesse*, *7*(1), 1-26.

Weikle, B. (2016, February 18). Teaching kids household chores is a valuable lesson. *The Toronto Star*. Retrieved from https://www.thestar.com/life/parent/2016/02/18/teaching-kids-household-chores-is-a-valuable-lesson.html

Weissbourd, R. (2009). *The parents we mean to be*. Boston, MA: Houghton Mifflin Harcourt.

Welter, B. (1966). The cult of true womanhood: 1820-1860. *American quarterly,* 151-174.

Werner, E. E. (1989). High-risk children in young adulthood: a longitudinal study from birth to 32 years. *American journal of Orthopsychiatry*, 59(1), 72.

West, M. L., & Keller, A. E. (1991). Parentification of the child: A case study of Bowlby's compulsive care-giving attachment pattern. *American Journal of Psychotherapy*, 45(3), 425-431.

Whyte, W. F (1943). *Street Corner Society*. Chicago, IL: University of Chicago Press.

Wiener, L.S., Spencer, E.D., Davidson, R. & Fair, C. (1993). National telephone support groups: a new avenue toward psychosocial support for HIV-infected children and their families. *Social Work with Groups*, 16(3), 55-71.

Wirth, L. (1927). *The Ghetto.* Chicago, IL: University of Chicago Press.

Woods, P. (1986). *Inside Schools: Ethnography in Educational Research.* London: Routledge.

Wynn, J. & Dwyer, P. (1999). New directions in research on youth in transition. *Journal of Youth Studies*, 2 (1), 5–21.

Yassi, A., Gilbert, M., & Cvitkovich, Y. (2005). Trends in injuries, illnesses, and policies in Canadian healthcare workplaces. *Canadian Journal of Public Health/Revue Canadienne de Sante'e Publique*, 333-339.

Zelizer, V. A. R. (1985). *Pricing the priceless child: The changing social value of children*. Pincenton, NJ: Princeton University Press.

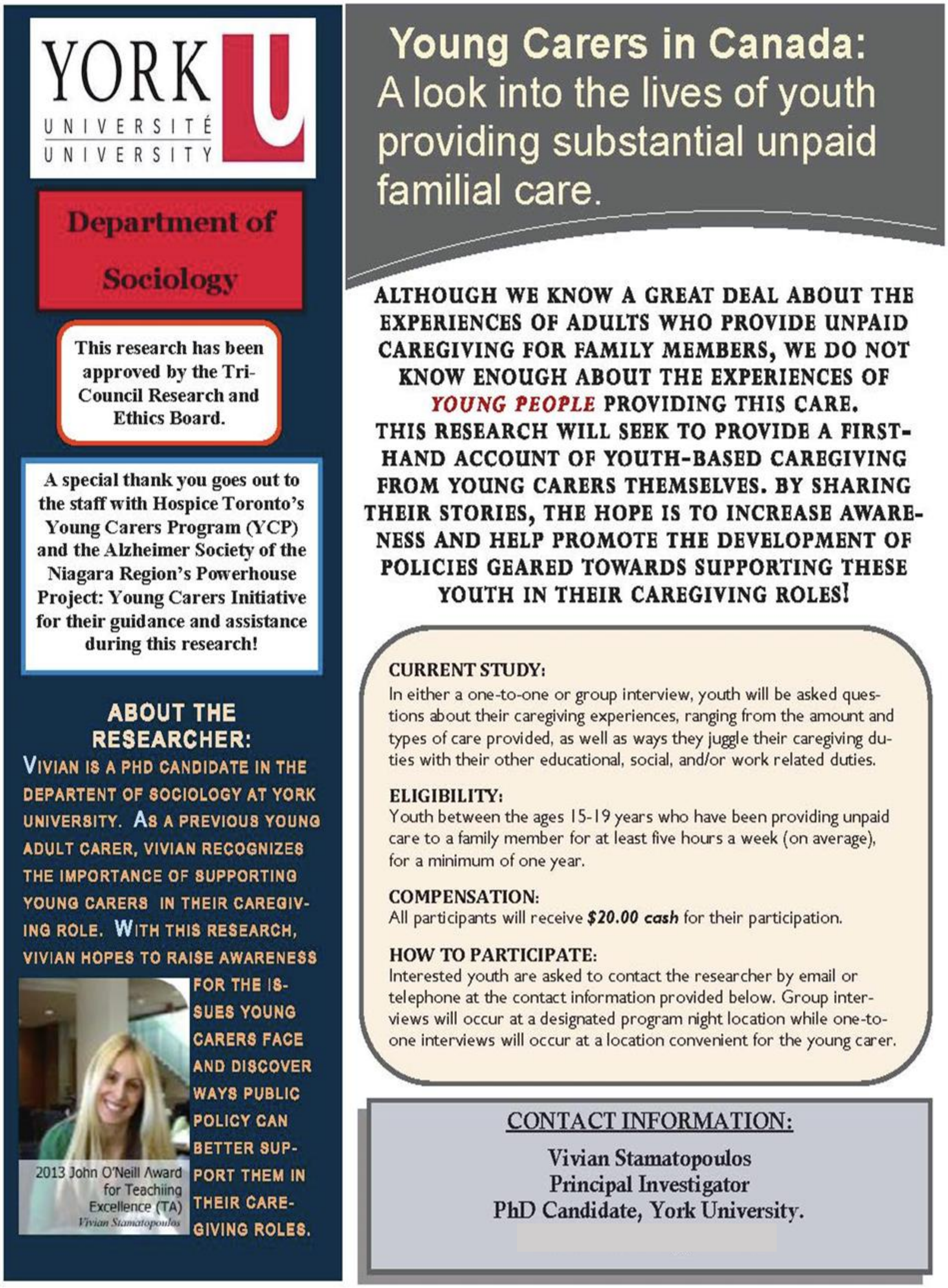
Zelizer, V. (2002). Kids and commerce. *Childhood*, *9*(4), 375-396.

Zelizer, V. (2005). The priceless child revisited. In J. Qvortrup, (Ed.). *Studies in Modern Childhood: Society*, *Agency and Culture* (pp.184-200). London: Palgrave.

APPENDIX A

Interview Schedule: Young Carer Program Staff	
Theme	***Questions***
Introduction & program specifics	**1.** What is your position with the ______(name of program)___? **2.** What are your main duties in this role? **3.** How many staff (and volunteers) currently work with the program? **4.** Can you explain what kinds of services/programs are offered by the organization to young carers? **5.** How many youth access your programs? Currently? In total? **6.** When did the program launch? **7.** Are there age restrictions to be a part of the program? **8.** Do you perform assessments or any qualification screening in order to register in the program? **9.** Do you know of any other programs that offer services to young carers?
What Youth Value:	**10.** What do you think the youth value the most about the program? **11.** Are there programs or services that young carers have expressed interest in that are not currently offered by your program? **12.** Do you the youth experience/report any emotional and/or physical consequences from their caregiving? **13.** Who are the youth primarily providing care to? (e.g., parents, siblings, grandparents?) **14.** Do you know how much, on average, youth spend providing unpaid care per day? …week?
Constraints / Challenges:	**15.** How is your program funded? **16.** Do you face any challenges/constraints with operating the program? **17.** What would you need in order to overcome these issues? **18.** Would you like to expand the services offered by your program?
Future Goals	**19.** What do you envision for the future of the program? **20.** How do you see the program moving in that direction (in terms of next steps?)
End of interview: "Thank you so much for taking the time to answer my questions. Do you have any comments you would like to make?"	

APPENDIX B



YORK U
UNIVERSITÉ
UNIVERSITY

Department of Sociology

This research has been approved by the Tri-Council Research and Ethics Board.

A special thank you goes out to the staff with Hospice Toronto's Young Carers Program (YCP) and the Alzheimer Society of the Niagara Region's Powerhouse Project: Young Carers Initiative for their guidance and assistance during this research!

ABOUT THE RESEARCHER:

VIVIAN IS A PHD CANDIDATE IN THE DEPARTENT OF SOCIOLOGY AT YORK UNIVERSITY. AS A PREVIOUS YOUNG ADULT CARER, VIVIAN RECOGNIZES THE IMPORTANCE OF SUPPORTING YOUNG CARERS IN THEIR CAREGIVING ROLE. WITH THIS RESEARCH, VIVIAN HOPES TO RAISE AWARENESS FOR THE ISSUES YOUNG CARERS FACE AND DISCOVER WAYS PUBLIC POLICY CAN BETTER SUPPORT THEM IN THEIR CAREGIVING ROLES.

2013 John O'Neill Award for Teachiing Excellence (TA)
Vivian Stamatopoulos

Young Carers in Canada:
A look into the lives of youth providing substantial unpaid familial care.

ALTHOUGH WE KNOW A GREAT DEAL ABOUT THE EXPERIENCES OF ADULTS WHO PROVIDE UNPAID CAREGIVING FOR FAMILY MEMBERS, WE DO NOT KNOW ENOUGH ABOUT THE EXPERIENCES OF *YOUNG PEOPLE* PROVIDING THIS CARE. THIS RESEARCH WILL SEEK TO PROVIDE A FIRST-HAND ACCOUNT OF YOUTH-BASED CAREGIVING FROM YOUNG CARERS THEMSELVES. BY SHARING THEIR STORIES, THE HOPE IS TO INCREASE AWARENESS AND HELP PROMOTE THE DEVELOPMENT OF POLICIES GEARED TOWARDS SUPPORTING THESE YOUTH IN THEIR CAREGIVING ROLES!

CURRENT STUDY:
In either a one-to-one or group interview, youth will be asked questions about their caregiving experiences, ranging from the amount and types of care provided, as well as ways they juggle their caregiving duties with their other educational, social, and/or work related duties.

ELIGIBILITY:
Youth between the ages 15-19 years who have been providing unpaid care to a family member for at least five hours a week (on average), for a minimum of one year.

COMPENSATION:
All participants will receive ***$20.00 cash*** for their participation.

HOW TO PARTICIPATE:
Interested youth are asked to contact the researcher by email or telephone at the contact information provided below. Group interviews will occur at a designated program night location while one-to-one interviews will occur at a location convenient for the young carer.

CONTACT INFORMATION:

Vivian Stamatopoulos
Principal Investigator
PhD Candidate, York University.
[redacted]

APPENDIX C

Interview Schedule : Young Carers

Theme	***Questions***
Amount & Types of Care Provided	1. Who do you provide care for? 2. How long have you been providing this care for? 3. On average how many minutes or hours a day of care do you provide? 4. Can you please explain the typical duties you provide as part of your caregiving?
Benefit Finding	1. Has your relationship with the person or persons you have been caring for strengthened during this time? 2. How rewarding have your caregiving experiences been during the past 12 months?
Seeking Social Support	**For Hospice Toronto Program Users:** 1. What services from Hospice Toronto do you use? 2. How has your time with Hospice Toronto benefited you? **For Non-Hospice Toronto Users:** 3. Are you aware of any programs in Toronto that you can access that provide support for individuals in your situation? 4. Have you looked into or got other people or organizations to help with your caregiving? E.g. other family members, nurses/personal support workers, community, spiritual or ethnic groups? 5. Has anyone provided you with financial support to help with your caregiving? 6. Is there any other type of support that you would like to have to help with your caregiving duties? For example, Home care / support provided to recipient, Financial support / Government assistance, Information / Advice, Emotional support / Counselling, Help from medical professionals, Respite care, Voluntary / Community services.
Outcomes of Care	1. Does your caregiving affect your family/ social life? For example, does it make you spend less time with your friends or other family members/loved ones? 2. Have your caregiving responsibilities caused strain in your relationship with family members or friends? 3. Does your caregiving affect the amount of time you spend on social activities or hobbies? 4. Has your caregiving caused you to feel lonely or isolated? 5. Does your caregiving affect your schooling? For example, do you have less time to do homework or study for tests/assignments? 6. …...cause you to be late to school or miss school altogether some days? 7. ….. prevent you from joining extracurricular activities? 8. …...affect your grades? How? 9. Does your caregiving affect your paid work or volunteering opportunities? For example, has it caused you to turn down work or volunteering opportunities for an organization? 10. If you work part-time (or full-time), has it caused you to go to work late, leave early, reduce your number of weekly hours, or take time off altogether? 11. Does your caregiving affect your physical health? For example, does it affect how much exercise you do? …what and how much you eat? Sleep? Smoke/drink? 12. Does your caregiving cause you spend less time relaxing or taking care of yourself? 13. Does your caregiving affect you mood? For example, has it caused you to feel irritable, stressed or anxious, overwhelmed?
Time Crunch	1. At the end of the day, do you often feel that you have not accomplished what you had set out to do? 2. Do you feel that you're constantly under stress trying to accomplish more than you can handle? 3. Do you consider yourself a workaholic? 4. Do you feel that you just don't have time for fun anymore? 5. Would you like to spend more time alone? 6. Do you plan to slow down in the coming year? 7. Do you feel trapped in a daily routine?
Coping with Care	1. In general, how have you been coping with your caregiving responsibilities? 2. What coping methods do you use? E.g. exercising, therapy, socialializing, religious practices, eating/drinking/ smoking?

APPENDIX D

YORK UNIVERSITÉ UNIVERSITY

Department of Sociology

Informed Consent Form

Study name:
Young Carers in Canada: A look into the lives of youth providing substantial unpaid familial care.

Researchers:

Vivian Stamatopoulos (Principal Investigator)	Dr. Norene Pupo (Supervisor)
PhD Candidate	Department of Sociology
Department of Sociology	Associate Professor
York University	York University

Purpose of the Research:
Despite the importance of research highlighting the impact of caregiving on women and families, the Canadian literature on caregiving, particularly on unpaid caregiving to the elderly, overlooks the experiences of youths who are increasingly taking on these responsibilities. This research seeks to uncover these experiences by interviewing young carers across the Greater Toronto Area.
To participate in this study, you must be a youth between the ages of 15-19 years who has been providing unpaid familial care for at least five hours a week, for a minimum of one year. Research will be conducted using face-to-face interviews and the results will be presented at scholarly conferences and in academic journal publications.

What You Will Be Asked to Do in the Research:
As a participant in this research, you will be required to take part in one face-to-face interview session, at a time and place that is mutually convenient, which will take approximately 60 minutes. During this time you will be asked questions related to your caregiving experiences, with questions ranging from the amount and types of care you provide and the ways you juggle your caregiving duties with other social, educational, and labour related duties. With your permission, I will audiotape and take hand-written notes during the interview. The audio recording will be used for transcription purposes only. If you prefer not to be audiotaped, I will take notes instead. Also, if at any point, you may skip questions that make you feel uncomfortable as well as stop the interview or withdraw from the project at any point. In the event you withdraw from the study, all associated data collected will be immediately destroyed wherever possible.
A $20.00 cash honorarium will be provided to thank you for your time.

Risks and Discomforts:
We do not foresee any risks from your participation in the research. If, however, a participant feels discomfort when discussing personal aspects of care, they may pause or cease the interview altogether. To help reduce any potential discomfort, interviews will be conducted in private locations and information on youth support services will be provided for every participant as part of a take-away package that includes the incentive.

Benefits of the Research and Benefits to You:
There is no direct benefit from participating in this study. However, findings from this research have the potential to inform individuals about the nature of young caring and help facilitate the development of policy and social programming geared towards young people who provide this care. Participating in this study can also provide an outlet for young people to share their personal caregiving experiences in a confidential and safe environment.

Voluntary Participation:
Your participation in the study is completely voluntary and you may choose to stop participating at any time. Your decision not to volunteer will not influence the relationship you may have with the researchers or study staff or the nature of your relationship with York University either now, or in the future.

Withdrawal from the study:
You may stop participating in the study at any time, for any reason, if you so decide. Your decision to stop participating, or to refuse to answer particular questions, will not affect your relationship with the researchers, York University, or any other group associated with this project. In the event that you withdraw from the study, all associated data collected will be immediately destroyed wherever possible. If you decide to stop participating, you will still be eligible to receive the promised pay for agreeing to be in the project.

Confidentiality:
All information you supply during the research will be held in confidence and your name will never be used in any reports or publications. Instead, any mention of respondents will be done with use of pseudonyms. Data will be collected using an audio-recording device and hand-written notes and any identifying information will be excluded from the recording process. Your data will be safely stored in a locked facility and only the principal researcher will have access to this information. The data will be stored for two years following the completion of the project. All data will be destroyed after that point. Confidentiality will be provided to the fullest extent possible by law.

Questions About the Research? If you have questions about the research in general or about your role in the study, please feel free to contact me or my Graduate Supervisor - Dr. Norene Pupo either by telephone at [redacted] or by e-mail at [redacted] You may also contact my Graduate Program, The Department of Sociology – 4700 Keele Street / 2060 Vari Hall,
This research has been reviewed and approved by the Human Participants Review Sub-Committee, York University's Ethics Review Board and conforms to the standards of the Canadian Tri-Council Research Ethics guidelines. If you have any questions about this process, or about your rights as a participant in the study, you may contact the Senior Manager and Policy Advisor for the Office of Research Ethics, 5th Floor, York Research Tower, York University, telephone [redacted] or e-mail [redacted].

Legal Rights and Signatures:

I ________________________________, consent to participate in the *Young Carers in Canada* Study conducted by Vivian Stamatopoulos. I have understood the nature of this project and wish to participate. I am not waiving any of my legal rights by signing this form. My signature below indicates my consent.

YOUTH AGREEMENT TO PARTICIPATE (For those between the ages of 16-19)

Signature__________________________ **Date**____________________
Participant

Signature__________________________ **Date**____________________
Principal Investigator

FOR YOUTH 15 YEARS OF AGE: PARENT/GUARDIAN PERMISSION TO PARTICIPATE

Signature__________________________ **Date**____________________
Parent/Guardian

Additional consent
The interview will be audio-recorded. Please check the box below if you consent to authorize the use of the associated transcribed interview data. Please note that the recording of the participant will not be associated with identifying information.

☐

APPENDIX E

YOUNG CARERS IN CANADA STUDY: Survey

Thank you for participating in the Young Carers in Canada research study! Please take a couple of moments to complete this survey that will accompany our interview.

1. What is your current age? __________

2. Are you:

○ Male ○ Female ○ Other

3. People in Canada come from many racial or cultural groups. You may identify with more than one group on the following list. Are you?

○ Caucasian (White) ○ Black ○ Chinese
○ Latin American ○ Filipino ○ Arab
○ Korean ○ Japanese
○ West Asian (e.g. e.g., Iranian, Afghan, etc.)
○ South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc.)
○ Southeast Asian (e.g., Vietnamese, Cambodian, Malaysian, Laotian, etc.)
○ Do not identify with any group
○ Other – Please Specify ______________________

4. Were you born in Canada?

○ Yes *(if yes, skip to Q.5)* ○ No *(please specify what country you were born in)*

____

5. How old were you when you first came to live in Canada?

____

6. What is your best estimate of your current total household income, received by all household members, from all sources?

○ Less than $25,000 ○ $75,000 - $99,999
○ $25,000- $49,999 ○ $100,000 or more
○ $50,000- $74,999 ○ Don't Know

7. Do you have any long-term health conditions, or physical or mental disabilities?

○ Yes *(if yes, please specify)* ○ No

____

8. Which family member(s) do you provide care to? (Note: Select more than one option if it applies to you)

○ Parent ○ Grandparent
○ Sibling ○ Other *(please specify)*

____

9. In an average day, how many hours of care or help did you provide to family member(s)?

_______ hours.

10. In an average week, how many hours of care or help did you provide to family member(s)?

_______ hours.

11. For what reason(s) do you provide this unpaid care or help? *(Select more than one option if it applies to you)*

○ Long-term physical illness or developmental disability
○ Alcohol or other drug problem.
○ Mental illness (e.g. Depression, Anxiety)
○ Parental absence (e.g. parents often away at work/ out of town etc.)
○ Other (please specify)

____

12. Are you currently in:

○ High school ○ College ○ University ○ Other (please specify)

____

13. If you are working at a job for pay, how many hours a week (on average) do you work? *(Note: please answer zero if you are not employed)*

________ hours per week.

14. If you are currently in high school, what are your post-secondary education plans? *(Note: If you are not in high school, skip to the next question)*

○ To attend University ○ To work (Part-time)
○ To attend College ○ Other: (please specify)
○ To work (Full-time)

____

15. In the last three months, have you ever missed school because of your caregiving duties?

○ Yes ○ No *(skip to Q.16)*

16. If you have missed school during the past three months, how many days would you say you missed? (Provide your best estimate if unsure).

____

17. In the last three months, have you ever missed work because of your caregiving duties?

○ Yes ○ No *(skip to Q.18)* ○ I did not work for pay during the past 3 months