



invisible intersections

Bringing the Experiences of Young Adult Caregivers to Public Discourse



TABLE OF CONTENTS

i	Terminology and Language Use
I	Foreword
2	Introduction
3	Methodology
4	Limitations
5	Findings
6	Discussion
7	Recommendations
8	Acknowledgements



TERMINOLOGY AND LANGUAGE USE

Caregiving

Providing care for the physical and emotional needs of a family member or a friend at home¹

Informal Caregiver

Individuals who provide ongoing care and assistance, without pay, for family members and friends in need of support due to physical, cognitive, or mental conditions²

Young Adult Caregivers (YACs)

An informal caregiver, whose age ranges between 18-24 years old, and is also a post-secondary student

Student Carer

Anyone who cares [and is a post-secondary student], unpaid, for a friend or family member who due to illness, disability, a mental health problem, or an addiction cannot cope without their support.³

Non-Caregiver

Someone whose age ranges between 18-24 years old, and is also a post-secondary student but does not engage in formal or informal caregiving

FOREWORD

I firmly believe that post-secondary institutions should work with their students to be the best students they can be, working with and not against the extenuating circumstances that many students are faced with. I believe my own lived-experiences and positionality within this research area as a former student-carer is significant to share because I know first-hand just how urgent and critical this work is. While I acknowledge and am grateful for the privilege I was still able to exercise within my own circumstances, this opened my eyes to a reality faced by more students than we know. This invisible population of student carers cannot exist on the fringe any longer.

Ashyana-Jasmine Kachra
October 2021



INTRODUCTION

This past year has signaled a shift in the national discourse of caregiving. In May 2021, the Federal Budget reflected a nationwide early learning and childcare program, a significant win for the country, particularly mothers and caregivers. The promotion of caregiving in public discourse, especially as the world became increasingly online over the past 18 months, presents an opportunity to broaden understandings of caregiving and bring to the forefront an invisible group in this category. Young Adult Caregivers (YACs) or student carers as they will be referred to interchangeably throughout this report, represent those aged 18-24 engaging in informal care work while simultaneously pursuing post-secondary education. In Canada, “existing estimates position Canadian youth as one of the largest global young carer groups, with more than 1.18 million between the ages of 15 and 24 providing some level of unpaid care in 2006, representing a 13.5% increase between 1996 and 2006.”⁴ Not only is this group seldom talked about, in the Ontario context measures rarely exist to identify carers as part of the non-traditional student group, and if these measures exist, stigma makes it difficult for these carers to self-identify. This report was created in part as an effort to dismantle the monolithic identity applied to post-secondary students in which they are perceived to have only the responsibilities of a student.

Distinguishing YACs from the general pool of adult caregivers engaged in informal caregiving is significant as current research shows that, due to both physiological and social reasons, YACs carry the burdens of caregiving differently than their adult counterparts. One of the reasons for this is that between the ages of 18-24 the brain is still not fully developed. Post-secondary institutions should be invested in the research and findings because preliminary research has shown that non-carers are not subject or predisposed to many of the stressors and burdens that YACs and student carers are,

which can create both strain and ambivalence between the student carer and their post-secondary institution and education.

Using a mixed methods approach, this report hopes to shed light on the harrowing reality of student carers and the very real effects faced as a result. There is a deep need for post-secondary institutions, both in Ontario and nationwide, to adopt a more urgent approach to recognizing and supporting this type of student. This report hopes to act as a pressure mechanism to inspire further research into the experiences and needs of this group and promote their inclusion in post-secondary data-collection.



METHODOLOGY

This research paper is guided by the following questions:

1. What does it mean to be a caregiver while also being a university student, and how does the experience of young adult caregivers differ from adult and youth caregivers...specifically why is this distinction important?
2. To what extent does caregiving affect university students in comparison to their 'non-caregiving' peers?
3. How can undergraduate students in Ontario be best supported as they balance their caregiving and student roles?

Research was conducted in three phases. The first phase focused on filtering results that were geographically relevant in the Canadian context. Once it became clear that not enough substantive research in the young adult and university student demographic existed, the geographic scope was broadened to include countries with similar characteristics to the Canadian university landscape. Based on similarities in factors such as government, cultural and ethnic make-up and ideals, countries including the United States, the United Kingdom, Australia, and the European Union (specifically the Netherlands, Germany, and Austria) were deemed viable research supplements.

The second phase expanded the geographic search parameters and then re-used the search terms from below to identify and pull literature on this topic. The third phase focused on narrowing the search again, where possible, to pull Ontario and Canadian specific testimonies from young adult caregivers, insight into the topic of young adult caregiving in the Canadian context, and relevant programs to help build the recommendations portion of the report.

Research was sourced through the following, non-exhaustive, combination of terms: ('Caregiver + University + Ontario;' 'Young Adult Caregiver

+ University + Ontario;' 'Young Adult Caregiving + University;' 'Student Carer + COVID 19;' 'Informal Caregiving + COVID 19 + Canada...').

To attempt to answer the guiding questions, this report relied on studies done in both the North American and European contexts that engaged undergraduate university students to speak to their experiences, or lack thereof, in the caregiving sphere. It was necessary to engage research in a global context because of the large gaps in Canadian research for this age demographic, an issue that will be further addressed in the limitations portion of the report. This report relies primarily on the qualitative data and statistical analysis produced by these studies. The following table highlights and displays the main studies used to gather information.

TITLE	REFERRED TO AS	DATE CONDUCTED	GEOGRAPHIC CONTEXT	RESPONDENTS	RESEARCH METHODS
The young carer penalty: Exploring the costs of caregiving among a sample of Canadian youth	Stamatopoulos 2015	2015	Canada	15 youth caregivers (or young carers) from both the Greater Toronto area and the Niagara Region of Southern Ontario	Qualitative Focus Group
Communal Orientation, Benefit-finding, and Coping among Young Carers	Areguy et al. 2019	2018	Canada	137 participants from two Canadian universities	Cross-sectional study, online survey
The Relationship Between Family Caregiving and the Mental Health of Emerging Young Adult Caregivers	Greene et al. 2016	2016	United States	353 undergraduates (81 past caregivers, 76 current/past caregivers, and 196 non-caregivers)	Quantitative analysis of a convenience sample
Sleep Quality in Young Adult Informal Caregivers: Understanding Psychological and Biological Processes	Hoyt et al.	2020	United States	76 participants (35 caregivers and 38 non-caregivers) from a public university in the USA (screened to determine caregiver status)	Controlled study
Expectations and Prospects of Young Adult Caregivers Regarding the Support of Professionals: A Qualitative Focus Group Study Expectations and Prospects of Young Adult Caregivers Regarding the Support of Professionals: A Qualitative Focus Group Study	van der Werf et al. 2020	2020	Netherlands	Twenty-five young Dutch adults (aged 18–25 years) who were growing up with a chronically ill family member participated in one of seven focus groups	Qualitative Focus Group

The information gathered by the studies is supported by peer-reviewed literature that covers the theoretical understanding of caregiving and relevant context, and has been used to help aid the explanation of study results as they correspond to the guiding questions of the report. Due to the important role that lived experience plays in qualitative social research,⁵ this research report will use a phenomenological approach which “stresses only those that have experienced phenomena can communicate them to the outside world. It therefore provides an understanding of an experience from those who have lived it.”⁶ Thus, studies with a qualitative approach were emphasized and the discussion portion of the report includes testimonies and quotes from grey-literature sources. The addition of non-peer reviewed literature was used for these testimonies as an independent OUSA Interview Series was unable to be conducted due to constraints around gaining institutional Research Ethics Board approval within the time allotted for the report process. The decision was made to include these testimonies due to the importance of including lived experience in research that hopes to inform policy for those directly affected by the issues and experiences in these discussions.



LIMITATIONS

Limitations have affected this report in three main areas: (1) limitations in research collection and result-finding; (2) limitations stemming from the scope of the report; and (3) limitations that come from the studies themselves.

Firstly, as this report aims to look specifically at the effect of caregiving on university students, it has been noted that this demographic is often muddled with the larger group of young adult carers. As a result, studies that use the term young adult caregivers (YACs) have age ranges that are not universally pre-determined but can range from 15 to 40. This scope is too large for the purposes of this research report, which aims to provide insight and analysis to inform and spark programming as well as policy changes for undergraduate students. This is not to say that young carers both above and below the target age range of 18–24 years old do not have relevant insight or experience that is applicable, nor is to say that this report is intentionally alienating the experience of mature students. Rather the research collected aims to show that YACs between the ages of 18–24, who are also attending university, are in a unique situation as they are not considered fully developed, putting them at risk for adverse effects from the perceived increased stress that comes from being both a caregiver and a student.

In terms of the study research presented in this report, there are two main limitations. The first is that none of these studies present longitudinal research, which means that it is difficult to claim trends across time, and the discussion presented draws upon a range of conclusions and trends that are snapshots in time. This should not discount the research presented but instead demonstrate a need for longitudinal research going forward, especially since trends across studies and contexts can still be drawn with the relevant observations/results presented. Second, as mentioned in the methodology section of the report, a wide array of studies had to be utilized due to the gaps in existing research; this includes differences in respondents, geographic

contexts, and study objectives to paint a larger picture of a very under-researched group. The aim of using differing studies is to be able to clearly establish whether caregiving as a post-secondary student should be seen as a significant additive burden that in turn deserves a specific response.

Lastly it should be noted that while caregiving is a deeply complex topic which manifests differently according to the specific type of care, malady, person, and circumstances, this report does not have the capacity to engage separately in all forms of caregiving, and rather speaks to the subject on a whole with its specific implications. Despite the limitations outlined, this report and the research used to guide it, provide valuable insight and evidence on the realities of university students that are also young adult carers.





FINDINGS

These studies demonstrate, despite differing in contexts and objectives, that young adults who are engaged in post-secondary studies and caregiving do face adverse effects emotionally and physically that their non-caregiving peers do not. This section briefly summarizes each study, and its findings. Where relevant and applicable, statistics and data will be shared.

Establishing Caregiving as an Additive Burden

The 2015 Stamatopoulos study aimed to probe both the benefits and penalties of YAC through a qualitative focus group of 15 Canadian youth aged 15-19 (a mix of both high-school and university students), interviewed between February and March 2015. The participants in this study had been engaged in unpaid care work for an average of 5.5 years with an average of 27 hours a week.⁷ The study described care tasks as age “atypical” given that YAC are engaging in tasks and responsibilities not typically associated with those their age. Stamatopoulos reported that, “despite probing both the benefits and challenges of early caregiving, the majority of accounts pointed to a wide range of personal and professional penalties incurred by youth’s caregiving, a finding similarly reported by Aldridge and Becker (1996) when reflecting on their research foray into U.K. young carers.”⁸ The study looked at the potential penalties of care work affecting various aspects of the young carers’ lives, including the effect these had on education, for example “participants often cited a daily struggle between satisfying their caregiving and educational demands, which in turn led to their feelings of being overwhelmed and exhausted.”⁹ These daily struggles resulted in the following: sleep deficits that would impact academic performance, breakdowns, failing courses, and in some cases having to repeat a year of school after being unable to keep up with all the responsibilities of both caregiving and school. The study also cited the following statistic from the

National Alliance for Caregiving (US-based) which supported its findings, “one in five U.S. young carers cite missing school or afterschool activities due to their caregiving and 15% indicate that their caregiving keeps them from doing schoolwork.”¹⁰ This study concluded that recognition of this group is extremely critical, especially as many YACs are “hidden carers”¹¹ a part of an invisible population.

The 2019 Areguy et al. study built on the work of the Stamatopoulos study. This study recruited 137 participants from two universities in Canada and used an online survey to gather data about caregiving, community, and benefit-finding. 46.7% of respondents aged 17-29, indicated they were providing a degree of informal care. The mean age of identified carers was 20.28 years, with 80.6% of them being female.¹² In reference to the National Survey of Student Engagement from 2018, “the ethno-racial and gender makeup of the sample is an accurate reflection of the current Canadian university demographic landscape.”¹³ The purpose of this study was to see if theories of adult caregiving would hold true for the young adult population being studied. Specifically, research on adult caregiving shows that when socially supported, through an inter-personal or community-oriented fashion, adults were able to benefit from positive effects of caregiving. Thus, it was hypothesized that given the community-based nature of post-secondary institutions, YAC’s would be able to cope better and find purpose in their care work through community-based support. However, the results of this study showed differently. Specifically, it was found that, “communal orientation was negatively associated with life and family satisfaction. This finding is contrary to studies in the adult caregiving literature which have suggested that communal orientation acts as a buffer for caregiver distress and burden.”¹⁴ An explanation for this put forth by Areguy et al., was that despite post-secondary institutions having a high-level of communal orientation, carers now have to split themselves between their care and student responsibilities. This can create ambivalence, and “negatively impact

overall life and family satisfaction”¹⁵ as YACs must balance between both their familial and post-secondary communities.

Table 1. Means and frequencies for demographic, communal orientation, benefit finding, coping and wellbeing variables among current young carers (n = 64).

Variable	M/%	SD
Demographics		
Age (17-29)	20.28	2.45
Gender (female)	80.60	-
Born in Canada	79.40	-
Communal Orientation	5.06	0.90
Benefit Finding	4.07	0.60
Coping		
Emotional Support	2.82	0.82
Instrumental Support	2.81	0.86
Active Coping	2.96	0.69
Planning	2.96	0.71
Acceptance	3.04	0.63
Wellbeing		
Life Satisfaction	4.80	1.29
Family Satisfaction	5.32	1.62

Fitsum Areguy et al., “Communal Orientation, Benefit-finding, and Coping among Young Carers,” *Child & Youth Services* 40, no. 4 (2019), 374.

The 2016 Greene et al. study is an American-based study that looked at the mental health effects of young caregiving, specifically “the relationship of family caregiving responsibilities and the mental health and well-being of individuals, ages 18–24 years, referred to as emerging young adults.”¹⁶ Through an anonymous mass online survey sent through the Office of the Registrar to students, this study had a convenience sample of 353 undergraduates (81 past caregivers, 76 current/past caregivers, and 196 non-caregivers). The most commonly reported tasks that were associated with current and past caregivers included: “walking, followed by feeding and dressing...act[ing] as companions, provid[ing] emotional support, and clean[ing/doing] laundry. Current/past caregivers were significantly more likely to be involved in organizing help from others and coordinating appointments as well as administering medication.”¹⁷ This study measured depression and other mental health related effects of caregiving using the 20-item Center for Epidemiologic Studies of Depression Scale (CES-D), presented on the survey as a scale of 0–3. Participants responded to items by choosing one of the following when asked “to think about how they felt or behaved in the past week”¹⁸: 0 (less than 1 day), 1 (1–2 days), 2 (3–4 days), or 3 (5–7 days). The level associated with each of the questions was then tallied to a total score between 0–60, “with higher scores indicating more depression symptomatology and a

score of 16 or higher indicating a clinical level of depression.”¹⁹ Anxiety was measured using the State-Trait Anxiety Inventory (STAI) and scored in the survey using the same methodology for scoring depression symptomatology outlined above, however the scale to measure anxiety was between 1 and 44, with scores ranging from 20–80. Results from this study showed that, “higher percentages of past as well as current/past caregivers (43.9 and 46.1%) had clinically significant CES-D scores (916) as compared to 29.1% of the non-caregiving group.”²⁰ For the caregiver group, the mean CES-D score was 18.80, with a standard deviation (SD) of 12.14, and for the non-caregiver group the mean CES-D score was 13.81, with a SD of 10.56. In terms of the STAI score, results “showed that caregiver status had a significant overall effect on state anxiety.”²¹ Further, “tukey post hoc tests revealed that current/past caregivers (M = 45.85, SD = 13.68) had significantly higher scores on the STAI state anxiety scale compared to the non-caregiver group (M=39.92, SD=13.34).”²² In both the CES-D score and STAI scores the difference between the caregiving group and the non-caregiving group was said to be that of medium effect, meaning that the caregiver group showed greater depression and anxiety symptomatology compared to the non-caregiver group.

*“The comparatively higher indicators of emotional distress in the caregiving groups suggest that the burden of caregiving coupled with university pressures and other factors likely makes young adult students more vulnerable to psychiatric distress.”*²³

The 2020 Hoyt et al. study is another American-based study that looked specifically at the sleep quality of both young adult caregivers and non-caregivers to draw a comparative analysis. This study recruited 76 participants from a public university, who were “heavily screened”²⁴ to determine their caregiving status. Ultimately, the total sample size was 73 caregivers and non-caregivers, post data-collection and screening. Participants were briefed on the study and sampling procedures in a laboratory setting to track sleep quality. At home, participants wore a device on their non-dominant wrist to track their sleep and collected 4 saliva samples a day for 3 days.²⁵ The participants had a mean age of 21 years and were predominantly female. While this study did not apply a specific gendered or cultural lens, it did state that “[B]lack participants were more likely to be caregivers than white par-

ticipants.”²⁶ Looking specifically at sleep quality, on a subjective level, “relative to non-caregivers, caregivers reported significantly more sleep disturbance and greater sleep latency in the prior 30-day period.”²⁷ The table below highlights the other sleep parameters measured as well as the difference between caregiving and non-caregiving participants. Overall, the “results suggest that caregiving is associated with several dimensions of diminished sleep quality including self-reported sleep disturbance and sleep latency, as well as objectively measured sleep fragmentation.”²⁸ As such, this study concluded that caregivers did establish a “high-level” of caregiver burden and “provides preliminary evidence for the negative impact of informal caregiving on sleep quality in this group.”²⁹ This study also looked at depressive symptoms, by measuring “relevant behavioral factors”³⁰ and used the Hospital Anxiety and Depression Scale (HADS). The study found that “caregivers had significantly more depressive symptoms than non-caregivers”³¹ however the average scores were within the normal range of the depressive scale used. Anxiety was also measured, and “caregivers reported anxiety symptoms in the “borderline abnormal” range, and this was significantly higher than the average HADS anxi-

caregivers’ functioning across many life domains, particularly among young adult caregivers who are simultaneously engaged in the developmental tasks associated with the transition.”³⁴

The 2020 van der Werf et al. study is a Netherlands based study that looks at the informal caregiving done by young adults who are also students with the aim of gathering insight into how service provision can be improved for YACs. Participants were recruited via an online survey. Those who were in a bachelor’s program or vocational education program and grew up with a chronically ill family member were asked if they would be comfortable in participating in a focus group. The study recruited 40 participants for the focus groups, conducting 8 focus groups with 5 participants each. Demographically speaking, 25 out of the 40 participants identified as female nursing students. Participants’ family members suffered from “both mental and physical disorders such as cancer, cardiovascular disease, depression, and addiction,” and “participants had experience with professional support and could state whether or not this support was adequate.”³⁵ The findings from the focus groups were organized into two themes: (1) the “process of approaching

Table 3 Subjective and objective sleep quality

	Caregivers M (SD)	Non-caregivers M (SD)	t (df)	95% CI	p value	Cohen's d
Subjective sleep parameters						
Sleep duration	0.93 (0.80)	0.59 (0.88)	1.70 (74)	−0.06, 0.71	0.092	0.40
Sleep disturbance	1.92 (0.55)	1.64 (0.58)	2.09 (73)	0.01, 0.54	0.040	0.50
Sleep latency	1.68 (0.82)	1.31 (0.69)	2.12 (74)	0.02, 0.71	0.038	0.49
Sleep-related daily dysfunction	2.14 (0.86)	1.80 (0.86)	1.73 (74)	−0.05, 0.73	0.089	0.01
Actigraphic sleep parameters						
Sleep duration (min)	317.07 (81.17)	353.33 (111.23)	−1.41 (74)	−78.94, 13.53	0.134	0.37
Sleep efficiency	93.80 (3.94)	94.66 (3.15)	−0.82 (74)	−2.41, 1.00	0.329	0.24
Sleep latency	10.16 (10.03)	13.12 (11.81)	−1.29 (74)	−8.61, 1.91	0.279	0.27
Sleep fragmentation	6.07 (3.71)	3.22 (2.24)	1.79 (74)	−0.32, 5.77	0.033	0.93

Michael A. Hoyt et al., “Sleep Quality in Young Adult Informal Caregivers: Understanding Psychological and Biological Processes,” International Journal of Behavioral Medicine 28, no. 1 (2020), p.11.

ety symptom score for non-caregivers.”³² Given the relationship between sleep impairment and both physical as well as psychiatric disorders,³³ improving the sleep quality of YACs should be considered urgent as well as access to affordable psychological services.

“The demands of caregiving can negatively impact

young adult caregivers”; and (2) “the types of support these young adult caregivers require.”³⁶

Under the first theme, “all participants mentioned the importance of professionals paying attention to their attitude”³⁷ as negative attitudes (or perceived negative attitudes) from general practitioners, community nurses, social workers, school psychologists,

and teachers often resulted in participants not requesting further support and many avoiding future contact with these professionals. This finding demonstrated that attitude is an important factor in service provision. Two other important factors identified under the first theme included: (1) recognizing young adult caregiver needs; and (2) the importance of keeping an open mind, especially when it comes to learning about the caregiver's family situation. Open-mindedness, "can be defined as an attitude that does not involve judgement or stereotyping [and] [p]articipants reported feeling judged because of their burden and family situation."³⁸

Under the second theme – which looked at the focus group responses in regard to services actually provided – the family situations of young adult caregivers was found to be difficult to understand by the professionals who were serving them. This affected how young adult carers received support, if at all. Key findings from the study included that young adult caregivers were overlooked by professionals as a result of lack of recognition and attention, and young adult caregivers "feeling vulnerable when initiating conversations about their family situation, inside and outside a support context."³⁹



DISCUSSION

The discussion portion of the report looks at four main areas. The first part, formally introduces the concept of the “Care Penalty” and the importance of a gendered lens when engaging in this research. The second part looks at ways in which remote working (from the onset of the COVID-19 pandemic) has affected young adult caregiving from March 2020 to the present and explores the potential impact of a future hybrid world on young adult caregiving moving forward. The third part draws comparisons between the findings of the five studies. The final part offers a macro-overview of potential recommendations that post-secondary institutions in Ontario can implement to better support students who are juggling both student and caregiving responsibilities.

The Care Penalty

The development of the term Care Penalty by England and Forbes in 1999 included their analysis that care work (both paid and unpaid) came with a “unique gendered care penalty.”⁴⁰ The gendered aspect of care work is extremely significant as through both essentialist characteristics imposed on women and the deeply entrenched gender roles in society, women have been tasked with “the overwhelming share of care activities.”⁴¹ Under this assumption, students as caregivers are at a disadvantage to their counterparts who are not engaged in care work – and this disadvantage is often disproportionately gendered. While a gendered analysis or lens was not used by the five studies guiding this research report, each of the studies did report that participants were largely female, and typically from non-white cultural groups. Similar to how this report focuses on young adult carers of a certain age demographic (18-24 years) to highlight the need for research on this group’s unique position, there should be pressure on applying a gendered lens to further research. Sarah O’Shea describes this urgency, on a global scale, where “female caregivers are significantly represented in student populations across the globe, yet insight into the dilemmas and

obstacles regularly encountered by these individuals remains noticeably absent.”⁴² Evidently, any available literature rarely includes both an age and gender relevant analysis/lens. The adoption of these lenses is critical because, as England and Forbes concluded, “the hours of work (paid and unpaid) have implications for the personal health and development of human capabilities”;⁴³ essentially, by taking part in care work, a person’s ability to compete in all facets of life – from school to work – with non-caregiving counterparts, is in fact limited.

The Pandemic Effect

When the COVID-19 pandemic hit, every aspect of life was disrupted. As lockdowns and public health guidelines pushed people into their homes, the line between school and home merged. While a challenging adjustment for all students across Ontario, YACs found themselves in an extremely precarious situation. The literature on the experience of YACs during the pandemic is extremely limited, proving difficult to assess exactly the extent to which the Care Penalty manifested and to push forth relevant recommendations for a hybrid world. That being said, it is critical to employ a pandemic lens to this research to ensure it’s relevancy. To that end, the following additional studies on informal caregivers more broadly, rather than disaggregated by age or student status, were used to better understand the effect of the pandemic on caregivers.

It is important to note that lockdowns and moving online not only blurred the line between school and care responsibilities, but in many cases also intensified care responsibilities due to the additional burdens brought by the pandemic.⁴⁴ A 2020 German study that surveyed 1000 informal carers found that, “25.5–39.7% [of participants] reported that the care situation rather or greatly worsened during the COVID-19 pandemic, especially for those caring for someone with dementia or those usually relying on professional help.”⁴⁵ An Austrian study found that while informal caregivers did not find a

great intensity increase in their care responsibilities, there was a significant difference in the psychological well-being between informal carers and their non-caregiving counterparts since the start of the pandemic.⁴⁶ A Canadian-based survey by Ontario Caregiver discovered that 54% of family caregivers had difficulty managing their caregiving responsibilities during the COVID-19 outbreak.⁴⁷ The survey also found that, “31% of caregivers are providing more than 10 hours of care per week, which is up from 26% before the pandemic.”⁴⁸ While these findings are not specific to the YAC age range, they do paint a larger picture of how informal care work was exacerbated by the pandemic. The following are results from a survey done by Regroupement des Aidants Naturels du Québec (RANQ) in Montreal to further highlight this picture.

- 20% of informal caregivers saw their expenses related to their role of caregiving increase by an average of almost \$900.⁴⁹
- 64% had no financial assistance, whether it was from the Canada Emergency Benefit (ECP), the Canada Student Emergency Benefit (CUSB), the Canada Emergency Wage Subsidy (CESG), Employment Insurance, Compassionate Care Benefits for a dying family member, or Caregiver Leave Benefits for a gravely ill family member.⁵⁰
- 57% occasionally felt they lacked resources to look after the person they care for.⁵¹
- 29% no longer feel very fit and have less and less energy.⁵²
- 25% say they are rather sad and irritable, no longer feel like taking care of themselves and feel overwhelmed.⁵³

Study Comparisons

Each of the studies explored in this report were conducted in different contexts, with similar but varying definitions of what it means to be a young adult caregiver. However, to make up for a lack of longitudinal research available, larger trends are identified by drawing upon the similarities and commonalities within the findings of the reports. Notably, each study recognizes the niche group that is YACs who are also students and identifies the unique situation of this group based on their age and social position.

For example, the Stamatopoulos study found that YACs did indeed suffer from an array of ‘penalties’ because of their care responsibilities that had effects on school performance and engagement. However similar to the other studies, such as the Hoyt et al. study, the Stamatopoulos study concluded that while their findings did demonstrate a care penalty for YACs, “we do not know enough about how the care penalty affects youth who are assuming the substantial care characteristically performed by their mothers”⁵⁴ due to limitations and research gaps in longitudinal data for YACs. Theories and hypotheses based on research on adult caregivers cannot be generalized to YACs, given that YACs aged 18-24 are not considered fully developed from a psychological and physiological standpoint,⁵⁵ and the added layer of being a post-secondary student. This was evident in all the studies: student YAC participants described feeling the extra burden of balancing both roles and were statistically more likely to be depressed and anxious than their non-caregiving counterparts.

Further, the Areguy et al. study hypothesized that because of the communal nature of post-secondary institutions, and the presumed relationship between community-oriented social supports and the positive effects of caregiving, that YACs would be able to derive more positive effects from caregiving. However, this study, along with others, indicated that YACs suffer from feelings of isolation and being torn between the two worlds of which they are a part of and have responsibility to. The Areguy et al. study cited Charles et al. who described this as a “push-and-pull” feeling “between their idealized life and their caregiver reality, and not being available to help in a caring capacity can lead to feelings of anger, guilt, and loss.”⁵⁶ This has both intrapersonal effects as well as effects on YACs engagement with their education. For example, in the van der Werf et al. study, participants discussed fears of judgement when disclosing their family’s situation or arrangement. These fears of judgement can lead to isolating oneself from support or avoiding confiding in friends. A previous statistic by the National Alliance for Caregiving indicated that YACs did not have as much time to partake in extracurricular activities than their non-caregiving counterparts. These findings suggest that for YACs to reap the benefits of a community-oriented institution such as a college or university, there must be support and efforts to

ease the push-and-pull tension so that they are able to meaningfully take part in post-secondary life.

On a physiological level, the Hoyt et al. and Jennifer et al. studies both found that YACs were more likely to suffer from troubled sleeping patterns and to report higher levels of anxiety and depression. Hoyt et al. relates their research on YACs' sleep to mental health issues by explaining, "the need to assist caregivers in improving sleep quality is paramount. Sleep impairment is associated with an elevated risk for a host of physical and psychiatric disorders [50–52], which are also associated with chronic stress. Despite the well-documented insomnia and related distress experienced by caregivers and caregiving-specific risk factors for insomnia, there are no empirically supported treatments to improve sleep among this vulnerable group."⁵⁷ All studies push for more research in the scope of young adult and student caregivers. Jennifer et al. explains this urgency through the perspective of the need for more research on the physiological effects of caregiving: "the psychosocial, behavioral, and environmental factors contributing to depression and anxiety in young adult student caregivers should be a research priority. This group may be at risk for continued poor mental health and difficulties in ongoing and future educational and occupational pursuits, as well as overall success in life."⁵⁸ Given the mental, emotional, academic, and occupational impact of the care penalties faced by YACs, and the lack of attention both in research and policy to support this precarious group, YACs should be a high priority for policy and lawmakers, both in and out of post-secondary institutions.

The Open University Case Study: A Scottish Perspective

The research on YACs during the pandemic has been particularly limited, however there are examples that can be used to inform how post-secondary institutions in Ontario can fill this gap and better support their YAC students. One example is the Open University in Scotland which not only has data available for how many carers are studying at the school – now a common data collection practice in the United Kingdom⁵⁹ – but also has information available on the experiences of "student carers during the pandemic." Ann, a student-carer from the Open University reflects on her experience, "You can lose yourself as a carer, as if you only exist

in relation to the person you care for..."⁶⁰ especially during the pandemic, where there is no structure to separate care responsibilities from school. The pandemic demonstrated just how fractured the experiences of student caregivers are, making now an opportune time for change.

The Open University is aware of the precarious experience student carers find themselves in and has developed a course for staff to help them better understand and support student carers. The course is unique in that it is centred on students' lived experience of caring and the impact on their ability to access, participate, and succeed in university.⁶¹ This is significant for a multitude of reasons, one being that "research shows that student carers are four times more likely to drop out of college or university."⁶² While this claim comes from a European context, in North America "student caregivers are considered non-traditional students; non-traditional students are more likely to drop out of higher education because of obstacles in their non-academic life."⁶³ Further, as established in the van der Werf et al. study, the circumstances of student carers were often overlooked and professionals did not have the necessary skills to aid this group. A course such as this can help to fill this gap by legitimizing the experiences of carers and providing staff with the tools needed to engage and support student carers. Therefore, to best support students to succeed, post-secondary institutions should work to identify this demographic in their schools and create best practices of support.

RECOMMENDATIONS

This report proposes three key recommendations that post-secondary institutions in Ontario can adopt to better identify and support student caregivers. The recommendations put forth are based on best-practices adopted by schools in the United Kingdom – the United Kingdom has been a leader in the realm of care, being at both the forefront of research and relevant data.

1) Data Collection

To best support student carers, they must be identified as a specific group within the school's population. Universities in the United Kingdom, such as the London School of Economics and Political Science and the Open University, ask incoming students to identify if they are carers or receiving care. By integrating such questions into school-wide surveys that have a section for self-identification, institutions can begin to map out a picture of student carers on their campuses. This visibility can potentially push universities towards a cultural shift in the way they view students who are both students and carers juggling both responsibilities. It is worth noting that student carers are a hidden population, and while beginning data collection is a step in the right direction, attrition should be accounted for. Thus, post-secondary institutions should look for innovative and sensitive ways to identify this population, in a way that validates their experiences rather than negatively singling them out.

2) Training

In the Canadian, and Ontario context in particular, student carers are not part of the public discourse. Thus, academic counsellors, professors, orientation leaders and others within post-secondary institutions, can be unfamiliar and potentially insensitive to the legitimate experiences of student carers who may require support to thrive in a post-secondary setting. By creating a course or training resource for staff and faculty, like that offered at the Open University, post-secondary environments can begin to

build awareness and inclusion of the student carer experience. Support staff can be better equipped to help student carers navigate the Care Penalty they experience, as well as the “push-and-pull” feelings that can limit their participation in their post-secondary environment. Further, by legitimizing the experiences of student carers, these students may feel more comfortable sharing their circumstances with relevant faculty and members of academic counselling, knowing that they will be met with support persons willing to help them make a plan for success rather than being berated for “taking on too much.”

3) Implementing Policy and Procedures

As mentioned, for student carers to be best supported, post-secondary institutions must be willing to work with this population/group to achieve success. As such, it would be beneficial to have a clear set of policies and procedures that student carers are able to follow when requesting support. For example, policies and procedures should outline what type of documentation is required when requesting an academic accommodation, and whether certain situations can be exempt from documentation, recognizing that documentation can be a barrier to receiving support. They should also indicate whether there is a form that can be used to request an alternative assessment measure for class participation, such as answering weekly prompts or contributing to class forums, if a carer is unable to actively participate in live online classes. It is important, however, that these policies and procedures are flexible, considering there will be circumstances not even the most thorough policy or procedure can account for, especially given the lack of understanding and hidden experiences of YACs. Post-secondary schools in Ontario should consider creating working groups with student carer members, to develop policies and procedures that value their lived experiences and are attentive to their needs.

CONCLUSION

As Canada begins to have a more serious conversation about informal caregiving and the implications it has, it is important that YACs are not left out of this conversation. It should be remembered that student carers are not a monolith, and future research must be done through an intersectional and equity-based lens. Factors such as gender, race, culture, and socio-economic class play a large role in the unique experience of student carers. Student carers should not be considered a fringe population, but instead an important group of students that post-secondary institutions should be supporting. Rather than to expect these students to demonstrate greater resilience, the aim should be to create equitable approaches to success.

This report demonstrated that the experiences of student carers must be brought into public discourse as this group does in fact face a penalty as a result of their caregiving role, including negative impacts on sleep, increased likelihood of depression, and barriers to their ability to fully participate in their studies. Applying a pandemic lens demonstrated how shifts to online education, and the pandemic more generally, had negative effects on informal caregivers. These findings and analyses were used to inform three important recommendations that post-secondary institutions in Ontario, and across Canada, should implement to make schools a more equitable place for student carers. The conversation around student carers is long overdue, and one that must continue through further research and commitment.



ABOUT THE AUTHOR

Ashyana-Jasmine recently graduated from Western University, with an Honours Specialization in Political Science. Currently she is studying in the United Kingdom as a graduate student at the London School of Economics, specializing in International Social and Public Policy.

ACKNOWLEDGMENTS

Eddy Avila – thank you for your leadership throughout the course of this project and supporting research in this very important area.

Britney De Costa & Malika Dhanani – without both of you, this report would not have been possible. Thank you for your constant support, understanding, expertise and edits that have helped shape this report.

Irum Chorghay – thank you for your dedication for bringing this report to life.

ENDNOTES

- 1 Sherri L. Sutton-Johnson, "A Phenomonological Exploration of Black Student Caregivers at Historically Black Colleges and Universities: Examining the Impact of Quality of Life from the Caregivers' Perspective," Master's thesis, Florida Agricultural and Mechanical University, 2020 (2020), p.18.
- 2 Canadian Caregiver Coalition, 2001), <https://www.ryerson.ca/content/dam/crncc/knowledge/infocus/informalcaregiving/InFocus-InfomalCaregiving.pdf>
- 3 "Student Carers Policy," University of Sterling, <https://www.stir.ac.uk/study/undergraduate/widening-participation/young-and-adult-carers/student-carers-policy/>.
- 4 Vivian Stamatopoulos, "The Young Carer Penalty: Exploring the Costs of Caregiving among a Sample of Canadian Youth," *Child & Youth Services* 39, no. 2-3 (2018): 118.
- 5 Taniya Mapp, "Understanding Phenomenology: The Lived Experience," *British Journal of Midwifery* 16, no. 5 (2008).
- 6 Ibid, 308.
- 7 Vivian Stamatopoulos, "The Young Carer Penalty."
- 8 Ibid, 191.
- 9 Ibid, 192.
- 10 Ibid, 182.
- 11 Ibid, 201.
- 12 Fitsum Areguy et al., "Communal Orientation, Benefit-finding, and Coping among Young Carers," *Child & Youth Services* 40, no. 4 (2019).
- 13 Ibid, 373.
- 14 Ibid, 376.
- 15 Ibid.
- 16 Jennifer Greene et al., "The Relationship Between Family Caregiving and the Mental Health of Emerging Young Adult Caregivers," *Journal of Behavioral Health Services & Research*, 2016, p.551.
- 17 Ibid, 555.
- 18 Ibid, 554.
- 19 Ibid.
- 20 Ibid, 557.
- 21 Ibid.
- 22 Ibid.
- 23 Ibid, 560.
- 24 Michael A. Hoyt et al., "Sleep Quality in Young Adult Informal Caregivers: Understanding Psychological and Biological Processes," *International Journal of Behavioral Medicine* 28, no. 1 (2020), p.7.
- 25 Ibid, 8.
- 26 Ibid, 9.
- 27 Ibid.
- 28 Ibid.
- 29 Ibid, 10.
- 30 Ibid, 8.
- 31 Ibid, 9.
- 32 Ibid.
- 33 Ibid, 12.
- 34 Ibid, 10.
- 35 Hinke M. Van Der Werf et al., "Expectations and Prospects of Young Adult Caregivers Regarding the Support of Professionals: A Qualitative Focus Group Study," *International Journal of Environmental Research and Public Health* 17 (June 16, 2020): p.4.
- 36 Ibid.
- 37 Ibid, 5.
- 38 Ibid.
- 39 Ibid, 7.
- 40 Vivian Stamatopoulos, "The Young Carer Penalty," 181.
- 41 Ibid.
- 42 Sarah Oshea, "'I Generally Say I Am a Mum First...But I'm Studying at Uni': The Narratives of First-in-family, Female Caregivers Transitioning into an Australian University.," *Journal of Diversity in Higher Education* 8, no. 4 (2015): p.255.
- 43 Vivian Stamatopoulos, "The Young Carer Penalty," 181.
- 44 Ibid.
- 45 Ibid.
- 46 Ricardo Rodrigues et al., "Care in times of COVID-19: The Impact of the Pandemic on Informal Caregiving in Austria," *European Journal of Ageing* 18, no. 2 (2021).
- 47 "2020 Spotlight on Ontario Caregivers," Ontario Caregiver Organization, December 10, 2020, [PAGE], accessed August 27, 2021, <https://ontariocaregiver.ca/spotlight-report/>.
- 48 Ibid.
- 49 The Regroupement Des Aidants Natuels Du Québec, "The Impact of the Pandemic on Informal Caregivers," RANQ: The Regroupement Des Aidants Natuels Du Québec, August 28, 2020, <https://ranq.qc.ca/en/the-impact-of-the-pandemic-on-informal-caregivers/>.
- 50 Ibid.<https://ranq.qc.ca/en/the-impact-of-the-pandemic-on-informal-caregivers/>
- 51 Ibid.
- 52 Ibid.
- 53 Ibid.
- 54 Vivian Stamatopoulos, "The Young Carer Penalty," 182.
- 55 Ibid, 180.
- 56 Areguy, "Communal Orientation," 376.
- 57 Hoyt, "Sleep Quality," 12.
- 58 Greene, "Family Caregiving and Mental Health," 560.
- 59 Marie-Pierre Moreau et al., "Carers Need More Visibility in Higher Education," *Wonkhe*, October 17, 2019, <https://wonkhe.com/blogs/carers-need-more-visibility-in-higher-education/>.
- 60 "Student Carers Need More Support," Open University in Scotland, July 06, 2021, <https://www.open.ac.uk/scotland/news/blogs/student-carers-need-more-support>.
- 61 Ibid.
- 62 Ibid.
- 63 Sutton-Johnson, "A Phenomonological Exploration of Black Student Caregivers," 18.

