Recognizing Heterogeneity: A Mixed Methods Approach to Language and Social Factors in Psychosocial Support Access for Canadian AYA Cancer Survivors.

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ABSTRACT

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Anna Maria Buhin

This thesis examines support programs for Canadian adolescents and young adult (AYA) cancer patients and survivors, using a mixed-method approach. Research suggests two demographic trends over the past decade that are noteworthy for my study. First, cancer diagnosis rates have increased yearly. Second, survival rates have improved exponentially. Within these trends, we find a growing number of AYA cancer patients and survivors. While growing, this population has been, unfortunately, insufficiently understood. AYA cancer patients and survivors experience poorer psychological well-being, such as higher rates of anxiety and mood disorders. Psychosocial support exists to improve the well-being of AYA cancer survivors and has been shown to impact them positively. Current literature, however, confounds all cancer survivors into a homogenous group and continues to compare them to the general population. While existing research considers barriers and buffers, such as language, cultural background, migrant status and income, not enough attention has been given to understand how within-category differences factor in accessibility, not just to healthcare but also to support programs.

Accordingly, this study set out to investigate the role of language differences in access, not only to healthcare, but also to psychosocial care for AYA cancer patients and survivors. The initial goal was to test if a parallel exists in accessibility issues across primary healthcare settings and tertiary psychosocial care settings, such as those exemplified by the social-recreational services provided by charities and foundations.

Quantitative analysis using data from Canadian Community Health Surveys establish that Canadian AYA cancer survivors are a heterogeneous subpopulation. Logistic regression analyses show that language spoken at home has statistically significant results in its impact of healthcare access. Other social demographic characteristics, such as income and visible minority status appear to have a stronger significant impact on healthcare access than the variables pertaining to language.

Interviews with six survivors/entourage and three foundation representatives suggest that language does not inherently cause accessibility barriers. For instance, ease of access also stems from successful communication with trusted medical professionals, which can be achieved with trust in the medical providers and ease in communication. When a provider and patient do not struggle with language barriers, communication comes more easily. In this way, language can impact access as catalyst for trusting relationships with providers rather than a direct barrier to understanding that there is support. Age, gender, and cancer status all impact access to care and its efficacy, which is closely related to social comparison among peers. The ability to relate to other survivors seems to be dependent on their social similarities. Further studies must continue to view AYA Cancer survivors as a heterogenous subgroup and avoid limiting research to the comparison of those who have had a cancer diagnosis and those who have not.

For the friends who have lost their lives to cancer.

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Chapter 1: Introduction:

Personal Perspective:

Up to this point in my life, nothing has been quite as distressing, yet impactful, as my cancer diagnosis. At the age of fifteen, I had to face my mortality but still consider my future, think of the worst-case scenario while doing my best to move ahead with school, and go through chemotherapy as I tried to prepare myself for the upcoming years of late adolescence and early adulthood.

While my treatments were efficient and led me to a full recovery, remission did not offer the definitive cut from the difficulties of cancer. It certainly was an improvement in the physical aspect of cancer with the end of treatments. In terms of social and emotional difficulties, such as issues returning to a regular school setting with my peers and the resurgence of mental health difficulties, they persisted.

I feel lucky to have had support from foundations and charities such as Leucan and the Tip of the Toes Foundation. Their programs and activities allowed me the space and tools necessary to improve my well-being once treatments had ended. While hospital stays and treatments gave me back my body and life, the programs of these organizations gave me back my independence and confidence. Attending camps organized by Leucan allowed me to be surrounded by other young survivors and not feel so alone in this process, despite being supported by my family. I also participated in a sailing expedition in the maritime provinces, thanks to the Tip of the Toes Foundation. The expedition literally and figuratively expanded my horizons and showed me that I could do so. In essence, when speaking for myself, I can

confidently say that having had this kind of support has improved my emotional well-being and provided me with the confidence to improve my position despite the diagnosis.

With a renewed perspective and recurring support for close to five years following my diagnosis, I was able to move ahead in my young adult life. Having started my education in social sciences while I was still participating in activities with Leucan and the Tip of the Toes Foundation, I was able to make some initial observations that led to the development of this project. The observation that motivated this work was that most of the other participants in these activities spoke one of our two official languages.

As the daughter of immigrants, born in Canada, I was able to find common ground with most of my cancer survivor peers, whether they were Canadian born or not. Though there were other survivors like me that did not have the same cultural background as a French Canadian "de souche," I had noticed that nearly every person surrounding me was primarily French-speaking. In addition, the groups I was in during the activities were formed primarily of Quebec or Ontario participants.

At that point in time, I was not aware of the social determinants of health as I am now; nevertheless it made me wonder where the cancer patients and survivors who do not speak the official languages fluently were. Did they struggle with finding the programs? Were they not interested in the activities? Or is there a larger issue with accessibility and language?

I understand my experience is circumstantial, although it was an observation that was seen throughout the multiple years I was involved with the foundations, either as a participant or a volunteer. As a survivor, I understand that cancer diagnosis and treatments impact everyone differently. The timing of the diagnosis, as well as the type of cancer, could influence outcomes

of a patient. As a sociology graduate, I am aware that social positions absolutely can have an impact on social outcomes following diagnosis. In my case, it had a direct impact on my education and my psychosocial development. Having to make up for lost time was not an easy task, especially with the weight of a cancer diagnosis on my mind.

Study goal and structure:

Though cancer is far from being the leading cause of death in Canada, it is far from uncommon. Roughly two Canadians out of five will experience a cancer diagnosis in their lifetime (Canadian Cancer Society, 2023, pp. 6). Concurrently, the five-year survival rate has gone up a significant amount since the 1990s, from 55% to 64% when encompassing all ages and types of cancers (2023, pp. 7). In sum, the Canadian cancer survivors' population is growing quickly. The same tendencies are visible in younger groups. There are more cancer survivors, but young cancer survivors have their entire lives ahead of them as survivors, and any issues and characteristics that come along with the title. In fact, in an article studying the potential plateauing of pediatric cancer survival rates in the United States, ranging from the 1970s to the early 2010s, the authors find that the survival rates of pediatric cancer patients specifically have vastly improved (Smith et al. 2014, pp. 2492). However, the article states that while the rates have improved, there are still issues to consider: "Despite the successes in identifying effective treatments for some cancers, at the end of the 20th century, >20% of children diagnosed with cancer still died from their disease, and many survivors experienced long-term effects that negatively affected their quality of life" (2014, pp. 2492). This study also states that diagnosis rates are slowly but steadily increasing, while survival has increased exponentially (2014, pp. 2501). The study by Smith and colleagues, thus, adds more weight to the importance of understanding the distinct needs of a growing and impressionable group of young survivors. This

shows that there are more cancer survivors overall, and that number continues to grow as survival rates and diagnostics improve. However, it also demonstrates that there is a need for support to survivors following remission and the end of treatment.

I move forward in this project with the assumption that adolescents and young adult (AYA) Canadian cancer survivors are the group that would most benefit from support given by foundations in the long term. This is mainly due to their young age, and adolescence and young adulthood being such a formative period early in their lives, which is when their social positioning and decisions on potential life direction could impact their growth into adulthood. This, in essence, is why AYA cancer survivors in Canada are the population of interest in the context of this thesis.

Theoretical Framework

This thesis functions within the framework of social determinants of health. In the study of population health, social determinants of health show that health is not only contingent on the biological characteristics of a person or a population, but also on their social characteristics. Inequalities within a society can have an impact on people's health Characteristics such as income can be an important factor in relation to health. In 1986, Wilkinson and Pickett's health index demonstrated the effect of income inequality on health outcomes when observing the scores of multiple rich nations: "The index comprised life expectancy, infant mortality rates, teenage births, obesity, mental illness, homicides, imprisonment rates, mistrust, social mobility and education" (As cited in Raphael et. al. 2019, pp. 15). The index clearly demonstrated the gap in income and education in the United States, and the parallel in health outcomes, so much so that causality could be inferred according to epidemiologic criteria at the time. In essence, the overall health of a society or an individual is linked to the social living and working conditions

of the person, which impacts the delivery of health-related care and the formation of health habits that can affect wellness down the line (Raphael et al. 2019, pp. 138).

In the context of this thesis, the notions of social determinants of health are used to understand accessibility to care outside of the hospital setting for adolescents and young adult Canadian cancer survivors. Though there is literature on youth cancer survivorship, many studies glaze over the differences among adolescents and young adults (AYA) and older adults and conflate them into one large group, despite their different needs. Focusing on adolescents and young adults will allow us to view the impact of cancer at a young age, which could be much more poignant to the upcoming changes they will soon face in the next formative chapter of their lives. To put it more precisely, social determinants of health, which are used in the study of a population, are useful in this project to show that AYA cancer survivors are a subpopulation.

To help AYA survivors overcome the difficulties that arise from their diagnosis, there exist programs that are created to help bridge the social and emotional gaps that survivors face, some of which cater specifically to the AYA cancer population, such as oncology camps and support groups. This thesis works with the theory of support as a stress buffer, where support is used to intervene in the probable event of a stressor, such as a cancer diagnosis, or as a remedy for the issues that arise from the stressor (Cohen & Wills, 1985, pp. 312). Cohen and Wills describe social support as being rooted in the relationships that a person may have: “It is likely that people who have more social companionship have more access to instrumental assistance and esteem support” (1985, pp. 313). In the case of Canadian AYA cancer survivors, support comes in the form of the programs and activities briefly mentioned in this chapter.

Part of this study is dedicated to adding to the already existing literature stating the positive impact of such programs. It also aims to understand the AYA cancer subpopulations’

characteristics and social determinants and how they may interfere with accessibility to this care. In this case, social determinants of health are not only useful for providing evidence that Canadian AYA cancer survivors are a subpopulation with distinct needs, but they are also a guideline for examining the issues in accessibility to formal support offered by charities and foundations. Understanding how social characteristics intersect is imperative in improving access to help that can alleviate the social and emotional rifts caused by a cancer diagnosis at such a young age. Being aware of the interactions can reduce the impact of a disruptive diagnosis on them at this important time. Focusing on teenage cancer survivors as young adults will allow a closer look into the next generation of survivors' needs and characteristics and may help lighten the immediate and long-term need for drastic mental and physical health interventions later in life.

Primary Argument:

I posited that language is an important buffer that can affect how easily someone can be involved in community support. As this project aimed to understand the impact of linguistic abilities, the assumption that immigration status could have an indirect impact on their well-being, due to a potential language barrier, was explored. I found that language barriers did cause some issues in finding and asking for help. I argued that those who do not have difficulties with the French and English languages have a much easier time finding the programs catering to them but also struggle less with the sign-up process. The idea is that easier access to programs can entail an easier time improving one's mental health and well-being following a devastating diagnosis. In short, the primary goal of this thesis is to point out and understand how certain characteristics that can be closely related to language, such as immigration status and ethnicity, can affect ease of access to care and support that is known to improve the well-being of pediatric,

adolescent, and young adult cancer survivors. These social characteristics have a similar impact on access to social care as they have on access to healthcare.

Research Questions:

In short, the goal of this project is to answer the following questions:

With a focus on those who have experienced healthcare in Canada from 2015 onwards, how do language barriers (among other barriers) affect an individual's access to formal support for AYA cancer survivors?

Is there a parallel that can be inferred between healthcare access and access to formal support for adolescents and young adult (AYA) survivors?

What could be done to facilitate access to programs and support offered by charities, non-profits, and foundations?

Key Concepts:

Some of the vocabulary used in this thesis project is simplified for ease of understanding in the context of the study. The terms are defined below.

Formal Support:

This is an encompassing term that includes all types of support offered by an entity that can be defined as a foundation or charity, with employees and/or volunteers that offer services and support to a group, such as AYA cancer survivors. These services are aimed at improving their situation caused by a life-altering experience, like a cancer diagnosis. The formality of this support stems from the organizational aspect of a foundation or charity offering it. Conversely,

informal support would be defined as support offered by those who are in closer relation to the person in need, such as friends and family members.

Survivor:

The use of the word survivor will often be used interchangeably with current cancer patients and those who are in remission. However, some individuals have had cancer recurrence. Others may be in active treatments as maintenance to keep an unchanging malignant mass from getting worse. These individuals may not categorize themselves in either position. There is an academic discussion about the use of the term as a blanket name for the group. Studies do provide insight into the problematic nature of using the term "cancer survivor" for any person who has had a diagnosis, regardless of the stage they are in. Those who are still in active treatment often reject the term due to the highly emotional impact of the diagnosis and ongoing treatments (Berry et al. 2019, pp. 422). There is also a debate about the factuality of the term "Survivor," given that it is often only used regarding cancer diagnosis and not other types of diseases (2019, pp. 423). However, there is yet to be an appropriate term developed to describe a group of people who have had a cancer diagnosis in their lifetime and are present to be defined as a group. Even with the debate in mind and though it may be an early limitation in this study, the use of "cancer Survivor" is meant to simplify the language and to consider the various cancer statuses that a person may have.

Programs:

The charities and foundations that are touched upon in this project offer a large variety of services to survivors and patients at varying stages of their lives following diagnosis. Certain services may be better defined as one-day activities or a one-time service, while others take place

over time, such as oncology camps or therapy. Other support can also be offered in the form of financial and/or social aid. In any case, it can be assumed that each service, or activity, is considered as a program which needs to be formed internally at each charity or foundation office. Therefore, the use of the word program can often encompass any service that is offered to help a cancer survivor.

Thesis Structure & Methodology:

To answer my research questions, this project is organized into chapters as follows.

To start, Chapter 2 presents a foundational literature review on the current literature on cancer survivorship in Canada and the overall impact of support offered by charities and foundations. Following this are chapters recounting the methodology and results from the research conducted for this thesis. Each of these substantive chapters also has its literature review that is tailored to the subject of the chapter.

Chapter 3 explores the question of the comparison of healthcare accessibility and accessibility to psychosocial care using quantitative analysis. It is used as the foundation upon which the rest of the study stands. It begins by establishing cancer survivors in Canada as a distinct subpopulation, where the focus is on young AYA Canadians who have either had cancer in their lives or have been in active treatment from 2015 onwards. It then observes how buffers interact for this specific group when accessing healthcare. To make a closer parallel between healthcare and formal support accessibility with language capabilities, the quantitative method chapter is presented to look at how certain social characteristics intertwined with language can impact access to healthcare for Canadian cancer survivors aged 18 to 39 years.

Chapter 4 focuses on access to programs that offer support to AYA cancer survivors, exploring language as a potential barrier. This chapter uses a qualitative methodology, interviewing survivors and their entourage about their experience with the programs and how they were able to be a part of it. Interviewing participants who have been involved in some type of formal psychosocial care outside of the hospital setting sheds light on the importance of understanding care not only within, but also beyond, hospital settings. It allows a view into how language and other social barriers may affect accessibility to those programs to answer the first research question. Speaking to this group is also useful in answering the second research question by allowing a comparison of the data developed in the previous chapter and the accounts of the participants spoken to.

Chapter 4 also has a section discussing the foundations' plans and methods in achieving a wider scope of survivors through improved access. Interviewing employees of the three main foundations spoken of by participants allows insight into how they plan to move forward in terms of ameliorating accessibility, and of the action they are already taking when speaking on the language barriers of participants. These discussions have taken place in the hopes of developing an answer to the third and final research question of this thesis.

Chapter 5 presents an analysis of both results chapters to further understand how language may impact access to care overall, and if there is a significant parallel between medical accessibility and access to support programs, as well as a focus on language as a potential barrier.

Chapter 6 concludes with final remarks on the results and speaks to the limitations of the project. This section describes future projects that could develop from the results of this thesis as well.

It is important to have an idea of what cancer survivorship in Canada looks like. This project takes the idea of changing survivorship within the scope of the social and societal implications of care for cancer survivors and patients outside of the hospital setting. It considers the social characteristics of a subpopulation, whose heterogeneity is often overlooked in literature, and contextualises characteristics such as income, minority & immigration status, and language in the scope of accessibility. In other words, the psychosocial support a person receives during and after treatment can have as much of an impact on positive outcomes following a cancer diagnosis as a successful medical intervention.

Chapter 2: Literature Review:

Current literature covers many aspects of this thesis's topics in depth, especially considering the topics of social support, diagnosis, survivorship, and accessibility. However, some knowledge gaps ought to be addressed. The following chapter will look at how prior research frames my study. I will first look at the literature on social support and state the theoretical perspectives of my project. Then I will reflect on diagnosis and survival rates in Canada. Following this, a report on literature focusing on cancer survivors' mental health and the impact of social support will be compiled before looking at literature on accessibility issues in healthcare and social services. Lastly, a conclusion will reiterate the poignant findings in the knowledge and show where this study can fit in the literature.

Defining Social Support and Theoretical Perspectives:

In its simplest definition, social support can be described as a helpful service given to a person in need, with which there is a positive outcome. Theorists have developed different models and definitions of social support that take into consideration more categories: "Type of support provided," "Recipients' perceptions," "Intentions of behaviours of the provider of support," "Reciprocity/exchange of resources," and "social networks" (Hupcey, 1998, pp. 1232). This focuses the definition more on the results and the needs addressed, rather than only on the intent of the provider.

This article also brings forward multiple models of social support, where it is not simply a direct relationship of providers and recipients, but can also be varied by the number of providers and recipients interacting, the directness of the support, and the reciprocity of positive outcomes. It can be a combination of a variety of factors that influence the trajectory and impact

of the positive interaction among all players involved: “Social support is a complex, dynamic, and fluid concept that involves interactions between recipients and providers.” (1998, pp. 1237).

Hupcey also critiques past studies on the concept of social support, claiming that one of the limitations is that there was an assumption that all recipients have the same or similar needs in terms of the type and number of services offered. They mention that the level of satisfaction with the support received is influenced by a person’s social characteristics and interacts with the norm of reciprocity demonstrated by providers (1998, pp. 1238). The theoretical perspective of reciprocity in social support systems is observable later in this thesis, as the perspective of the foundations themselves will be considered in understanding not only the impact of support, but also their accessibility.

Another theoretical perspective of social support that is apparent as this project moves forward is the social comparison theory, in which “a person develops their self-concept by comparing themselves to others in their chosen reference groups” (Langford et al. 1997, pp. 96). Appraisal support and informational support both offer the recipient the knowledge needed to alleviate any stress or issues following a difficult event, and the confidence that they are acting accordingly and appropriately given their circumstances: “Informational support assists one to problem solve […] Appraisal support involves the communication of information which is relevant to self-evaluation rather than problem-solving. […] [It] encompasses expressions that affirm the appropriateness of acts or statements made by another.” (1997, pp. 97). In other words, it improves one’s knowledge of their circumstances and their confidence, which in this context could be observed in situations where the survivor is being informed of their cancer outcomes or better courses of treatment and care.

Another article states that social support, despite having a fluid and somewhat open definition, impacts health and morbidity in many ways. One is by "regulating thoughts, feelings and behaviours," another is by offering a context in which a person can create a "sense of meaning in life," and yet another is by giving the recipient the tools, whether tangible or not, to develop and maintain healthier habits and behaviours (Callaghan & Morrissey, 1993, pp. 204). However, the authors do mention that the perception of support may be more impactful than the amount of support given. In other words, one may have received a lot of support in the eyes of the provider, but, if the beneficiary feels they do not gain from it, no amount of support will compensate. Conversely, a recipient may have much more positive outcomes despite not receiving as much support as the next person (1993, pp. 208).

All three articles reviewed above follow a general guideline when discussing the meaning of "social support." It is defined as "help" when help is needed, whether it is informational, emotional, financial or other modes of support. While the theoretical definition of social support has not been pinned down definitively, it will be defined as such for this project:

Social support is understood to be a positive interaction between provider and recipient, in which the recipient is being helped in their predicament or situation that inhibits the progression and flow of their lives, as it would, had there not been a negative event such as a cancer diagnosis. The support offered would be in the form of information, resources, emotional and physical assistance or guidance. In this context, social comparison is often an indispensable tool in both the administration of support and in the measurement of positive perception and acceptance of the support offered. If a recipient cannot view themselves within the group, the providers are offering support to, then they are more likely not to view the support as adequate or necessary. In short, support is the result of aid given to a recipient by a provider, which was

received positively and has resulted in a positive outcome that otherwise would likely not have happened without the intervention of the provider.

Diagnosis and Survival Rates in Canada:

As the science behind diagnoses and treatments evolves, survivorship changes along with it. A widespread belief is that reductions in cancer-related morbidity and mortality are based primarily on biological interventions, effected through improvements in treatment. However, assuming that quicker diagnosis, a streamlined treatment protocol and robust biological research would be the sole cause of a survivor's well-being post treatment diminishes the psychosocial needs of survivors.

The Canadian Cancer Society explains that survival statistics for the individual must also take into consideration other characteristics to make a more educated guess on prognosis outcomes for the patient. The first thing to consider in prognosis estimates is cancer staging[1]. Age is also a strong indicator of survival rates, as well as the patient's coping abilities following diagnosis and treatment (Canadian Cancer Society, 2025).

Net survival decreases with age, despite the type of diagnosis and staging. Adolescents and young adults (defined in the reference study as being aged 15 to 44) have a significantly better net survival percentage across the board, even when considering the staging and the type of diagnosed cancer (Ellison & Saint-Jacques, 2023, table 1). In other words, as the diagnosis rate tends to increase, so does survival. Young Canadians have better survival rates across the

[1] Staging is used to provide information about a cancer diagnosis based on the location it was first found and how much cancer is in the body. It can also consider the spread of the illness across the body (Canadian Cancer Society, 2025).

board, and so the group of adolescents and young adult (AYA) cancer survivors is an ever-growing population with distinct needs, which should be addressed.

Survivorship & Mental Health:

As young cancer survivors and long-term survivorship continue to accrue, they begin to make up a much more important portion of the general population. Due to its growing nature, there is value in the assumption that it is also becoming an increasingly heterogeneous group. The following section will explore the notion of cancer survivors as a subpopulation through literature, demonstrating that there are distinctions to be made among the group, and not only between them and those who have never had a diagnosis.

The following section also aims to establish that, although it is a diverse group, cancer survivors may present more mental health disparities than the rest of the population, but also among themselves.

Cancer Survivors as Subpopulation:

A previous study focused on the AYA cancer survivor age group stated that they are at a higher risk of developing mood and anxiety disorders, but not necessarily a substance abuse issue, following their diagnosis. They have also pointed out that previous studies often lump adolescents with pediatric oncology and young adults with the older age group, when in fact they tend to have needs of their own, given that they are in the age range where the onset of mood disorders is much more prevalent, regardless of a diagnosis (De et al., 2020, pp. 15). The study also points out some variance within the cancer population, but mostly in terms of gender, stating that women more often report mental health issues than men. They also report it in terms of the type of cancer at diagnosis: "The risk of PTSD was higher in individuals with bone cancer, CNS

cancers, HL/NHL, leukemia, soft tissue sarcoma and neuroblastomas compared to sibling controls. The highest-risk groups were those with [Hodgkin's lymphoma], [non-Hodgkin's Lymphoma, or acute leukemia" (2020, pp. 17). While this article does provide a look into the group of AYA cancer survivors as a distinct population with varying needs, it continues to generalize their mental health outcomes on a few characteristics, rather than having a multi-sectional perspective on mental health outcomes and what may impact them.

A report on previous studies does show that there is some literature on the impact that psychosocial status may have on mental health. The authors point out that cancer survivors tend to report poorer mental health than their healthier counterparts, despite most survivors not reporting mental and emotional distress (Mertens & Marchak, 2015, pp. 93). This report compiled a list of risk factors associated with higher levels of distress: "Female sex, annual household income less than $20,000, lack of health insurance, presence of major medical conditions, and treatment with cranial radiation and/or surgery" (2015, pp. 94). This shows that there are many other factors at play when observing mental health outcomes in this age group. However, researchers also attach a biological aspect to mental health issues by pointing out that those who have received cranial treatment are at a higher risk. Mertens and Marchak continue to imply that a specific type of cancer could have an impact on emotional well-being (2015, pp. 94). In other words, once again, cancer survivors tend to report worse emotional well-being than their counterparts, but studies do not seem to delve deeper into social characteristics.

Another systematic review of literature that is focused on the mental health outcomes of AYA cancer survivors also reiterated similar results. AYA cancer survivors tend to have worse mental health than those who have never had cancer in their lives (Tanner et al., 2023, pp.18385). However, nearly half of the studies they have observed stated that there is no significant

correlation between having worse mental health and being an AYA cancer patient and survivor: "In one of these studies, the AYA cohort included patients and survivors, covering from 0 to 60 months post-treatment. A second of these studies focused on patients, with the remaining three studies looking at survivors only" (2023, pp.18384). The studies that had reported no correlation between mental health status and cancer status had focused on either those who are still in active treatment or those who have been in remission long term. This could suggest that 0 to 60 months post-treatment is the period where a survivor is most at risk of reported low mental health and well-being. However, Tanner and colleagues state that there is a need for more in-depth longitudinal studies. The few that have been identified have not compared the participants to a control population. They were also published before 2010: "Ultimately, there is a distinct lack of longer-term follow-up and comparison to show the evolution of mental health in this population over time—especially longer periods—compared with healthy peers" (2023, pp.18389).

In other words, the literature generally agrees that AYA cancer survivors and patients tend to report more instances of having mental health issues such as anxiety or a mood disorder. Post-traumatic stress disorder is also touched upon multiple times in these articles. It is also stated that often the type of cancer can impact the degree to which a survivor may present symptoms. In most cases, there is still a need to further research into the group as a subpopulation that is distinct from the general population.

The Impact of Social Support on Cancer Patients and Survivors:

The use of programs and services that are meant for this population can significantly improve the social outcomes of survivors and patients. Prior research demonstrates that interventions such as care plans for survivors were reported to have meaningful positive impacts on physical, emotional, and psychosocial wellness (Howell et al. 2011). It goes so far as to

question the optimal level of involvement of psychosocial care programs to the survivor, all while prescribing extended support past the hospital setting and into the remission phase of the survivors' life: "Survivors should have access to coordinated, interdisciplinary, multi-component psychosocial and supportive care services during the transition from active treatment to extended survival." (2011, pp. 271). This substantiates the claims of this thesis that the formal support catering to a specific type of person, in this case, AYA cancer survivors, is beneficial and should be further understood.

At the same time, reviews on pediatric oncology camps report the therapeutic impacts of such activities on young survivors and patients, as well as their families. Earlier studies highlight positive outcomes in terms of self-perception and self-actualization. These studies cite an improvement of growth and evolution in terms of "cancer knowledge, mood, self-concept, empathy, and friendships" (Martiniuk et al. 2014, pp. 786). Later studies often echo these sentiments and bring forward notions of renewed independence for the overprotected sick child, which in turn improves their quality of life down the road by offering a perspective of near-limitless possibilities, in comparison to the previous sheltered state of mind of the young patients and survivors and their well-meaning families (2014, pp. 786).

Other studies on adolescent and childhood cancer survivors look at the impact of social support on their adaptability and adjustment following a diagnosis and even after the end of treatments. At first glance, increasing the amount of social support appears to directly and positively impact the adjustment levels of young patients and survivors. However, such support is not the only influence on general positive outcomes, whether social or biological. Family functioning, meaning the degree to which families remain cohesive and open in expressing needs and feelings, had as much, if not more, influence on lowering the child or adolescent's level of

psychological distress and increasing social competence following a devastating diagnosis (Woodgate, 1999, pp. 206).

A recent study focusing on the impact of social support on cancer survivors points out that social support has a general positive impact on the well-being of survivors, apart from physical health. Poorer physical health is reported, possibly because they are more likely to seek out social support more often (Schulte et al., 2021, pp. 1330). They reiterate what is mentioned in previous studies that ongoing social support is extremely valuable to all cancer survivors, but most critically to AYA survivors: "Survivors of AYA cancer often cite a sense of isolation, both among their healthy peers, who are not able to relate to the experience of cancer, but also among fellow patients with cancer, feeling too old compared with pediatric patients or too young compared with adult patients" (2021, pp. 1330). Essentially, this study finds that social support is likely to result in a somewhat better quality of life for the survivors receiving the support.

These results bring up an interesting perspective where there is a need to consider the social differences between the group of cancer survivors in Canada, especially when we are discussing the role of social support on survivorship. However, in this literature, it is established that social support has a positive impact on the survivor, which allows us to continue in this project with this assumption.

Accessibility Issues:

Issues in accessibility will be defined by the following themes: Social health disparities and language issues in accessibility.

Social Health Disparities:

Access to healthcare is often affected by the patient's social positioning. A person with fewer resources could struggle to reach adequate care that is needed, notwithstanding the social implications that can affect one's overall health and health habits. For example, a study comparing rural and urban areas ease of access to medical services and care found that rural areas tend to have less difficulty accessing their preferred provider promptly and having services offered to them in a more informal way, which is not commonplace in urban areas. Rural areas, despite having less specialized providers nearby, score much better in accessibility than urban areas, which report having difficulties on all fronts related to accessing a preferred provider, the time frame until consultation, and in terms of geographic location (Haggerty et al., 2014, pp. 97).

As mentioned, access to resources can impact how one seeks care, but also their overall health. A 2017 article focusing on children's health care access in the United States argues that "access and interaction with the healthcare system are shaped by family socioeconomic position" (Kramer et al., 2017, pp. 7). This, in turn, directly influences the health status of the person in question, which in this literature is the children in the families. The researchers measure healthcare access to insurance, a usual and stable healthcare provider, and the health habits within the medical system, all of which are likely influenced by income and educational levels. Those with a lower income or a lower level of education tend to have more difficulties in all three accessibility categories mentioned (2017, pp. 7).

Another article defined access to healthcare as the "interaction of determinants pertaining to characteristics from individuals (e.g., the place where they live, their economic resources, and their social status), and of services (e.g., quantity, location of facilities, costs)." (Levesque et al.,

2013, pp. 6). It demonstrates that factors outside of the medical system can and do have an influence on accessibility to crucial healthcare, which, in turn, can impact the health outcomes of people seeking services, regardless of whether they have ease of access or not.

Another study based in the United States identified other barriers in healthcare accessibility that are connected to immigration status. The authors of this study state that, despite many immigrant families being eligible for services in health care, they tend not to apply. Citing language barriers, trust issues, and "the complexity of the application process" (Perreira et al., 2012, pp. 6), this study also mentions logistical barriers such as transportation issues and work obligations that create both physical and often financial barriers to accessing healthcare and social care. The report also states that there is an issue of readily available information on the services, pointing out that most immigrants are made aware of services through "word of mouth" (2012, pp. 10). The most direct barrier mentioned is the language barrier, creating a difficulty in both finding the appropriate forms and filling out the sign-up process for both the services needed and the programs offered to them (2012, pp. 10). This type of issue is what may be observable in the sign-up process for support programs offered to Canadian AYA cancer survivors. Language barriers could directly impact accessibility to social care and formal support.

Language Issues in Access:

Literature suggests that language issues are present in Canada when focusing on accessibility to healthcare. Having to navigate the Canadian healthcare system that functions primarily in English or French, depending on the province of residence, can cause feelings of frustration and lack of trust for the families seeking support for their sick child, according to Gulati and colleagues (2012, pp. 576). These results are often linked to the cultural implications

of being an immigrant family. The authors state that difficulties speaking official languages in Canada have led to frustrations and misunderstandings by parents when having to care for their sick child, which, in turn, could result in less successful medical interventions. They also mention culture as a barrier to healthcare access and positive health behaviours, stating that immigrants of a visible minority more often “tend to be less active participants in making decisions about their healthcare” (2012, pp. 576), implying that they more often have a passive role in seeking healthcare, and thus not receiving the care needed. This may also reflect the cultural practices that are more common in Canada, where certain immigrants may have discomfort in the way healthcare is provided.

Conversely, many immigrant parents still express having adequate or good healthcare by their providers, and feel their child is supported by the medical staff in hospitals. However, there is a lack of community in that environment with whom they would be more comfortable. The article states that “immigrant parents’ sense of loneliness and lack of belonging indicate that there is limited awareness about how to effectively socially integrate immigrant families with language barriers in the healthcare process” (2012, pp. 577).

Experiencing a language barrier while seeking healthcare is not an issue that is unique to immigrants arriving in Canada. A study on language minority francophones in Canada points out that the experience of “increased stress and decreased confidence [led the patient to feel] that care received was inappropriate” (De Moissac & Bowen, 2019, pp. 29). Similarly, they report that francophone Canadians living outside of Quebec have difficulties receiving the right diagnosis and receiving the necessary treatment within a reasonable delay. These issues are linked to poor communication among patients and providers, despite speaking French, which is one of the country’s official languages (2019, pp. 29). The study did not look at the situation of

anglophone patients within the province of Quebec, but the issues experienced by francophone Canadians in the rest of Canada appear to parallel the reports provided by the literature on language barriers that are experienced by immigrants in any country in North America.

Conclusion

In short, the literature states that social support is a tool that is generally viewed as a positive aspect in both healthcare and long-term survivorship for AYA Canadian cancer survivors. Reports also state that the impact is significant when taking into consideration the mental and emotional well-being of the survivor, which is often found to be less than ideal when compared to their age group that has never had a cancer diagnosis.

The literature also states that healthcare access is often affected by social positioning. Many studies point to income and immigrant status as having a stronger influence on one's ability to successfully navigate the healthcare system.

Lastly, language also appears to have an influence on access to and quality of care one is provided, regardless of their immigrant status.

Considering that language has such implications for access to healthcare, it is plausible that it may have a similar impact on access to support programs. Literature based in the United States suggests that language barriers prohibit patients from easily using forms that are required to navigate the American healthcare system. Forms, in the context of programs and services offered by charities and organizations meant to aid AYA cancer survivors in Canada, thus represent an important consideration for scholarship. A more detailed account of accessibility to healthcare for Canadian AYA cancer survivors will be developed in the next chapter. The correlation between language and access to programs will be explored in the following chapter to

see if a significant parallel can be made between the two, and whether we can continue to study potential barriers to psychosocial care in the same fashion as the barriers we see in healthcare.

Chapter 3: Healthcare Accessibility in Canada— Laying a Foundation to Understand Access Barriers for Canadian AYA Cancer Survivors as a Subpopulation.

Introduction

In this chapter, the concept of accessibility will be explored in the context of the Canadian healthcare. Attention will be paid to the social characteristics and demographics that may interfere with the ability of adolescent and young adult (AYA) cancer survivors and patients to receive adequate healthcare. The main goal in studying healthcare access (when the project's theme is accessibility to formal support such as programs and psychosocial care outside of the hospital setting) is to first understand adolescent and young adult Canadian cancer survivors and patients as a subgroup with mental health disparities and potential barriers resulting from their social positioning, but also their cancer diagnosis. In the quantitative analysis to follow a general comparison be made between survivors and those who have not had a cancer diagnosis. This chapter argues and demonstrates that there are differences within the cancer survivor subpopulation that affect access to care, and impact accessibility to programs in a similar manner. Treating cancer survivors as a distinct heterogeneous subpopulation, with needs specific to them, allows a better view on accessibility to care. It also adds to the literature that often only focuses on the comparison between cancer patients and survivors and the rest of the population.

I arrived at the argument made in this chapter by beginning with the following questions:

- *After establishing a clear difference between cancer survivors and patients and those who have never had cancer, should future studies observe cancer survivors as a heterogeneous subpopulation, rather than a homogenous group within the Canadian population?*
- *Do cancer survivors in different economic and social positions experience unmet healthcare needs and/or lower well-being?*
- *Do language and immigration status correlate with the unmet healthcare needs of AYA cancer survivors (i.e., those who currently have or have had cancer in their lifetime)?*

The first section of this chapter will show some key concepts through a brief literature review, before moving on to the quantitative analysis methodology. The literature review will elaborate on the social determinants of health and examine how prior literature recounts AYA Canadian cancer survivors as a subpopulation, before exploring what has been said on language barriers and healthcare. Afterwards, the results will be presented and discussed; and a link will be drawn between accessibility to medical care, on the one hand, and accessibility to formal support, on the other hand. This focus will provide a segue into the following chapter.

Literature:

The following subsection focuses on the current literature speaking on the social health demographics of Canadian cancer survivors. It also delves into literature that explores how

language can affect accessibility to healthcare[2]. To contextualize health demographics and language barriers, a brief look into the social determinants of health notions will be brought forward before delving into this section's secondary subject matter, which is the impact of a language barrier to care.

Since much of the literature continues to analyze cancer survivors as a homogenous group, I see a need to shift the focus and to assess their needs as a heterogeneous subpopulation. Studies on a societal scale demonstrate just how social characteristics can impact one's health (Levesque et al. 2013). Studying AYA cancer survivors as a subpopulation should also be applied in research on populations of cancer patients and survivors.

Social Determinants of Health:

As discussed in Chapter 2, social determinants of health involve the interaction of social positioning within the medical system that a patient can act in, which in turn can affect their health outcomes. Access to resources such as income and education can affect the way a person can access care. Having easier access to resources often tends to result in better health and well-being, as there is less difficulty receiving the care needed when there is a health issue to address. An article by Kramer and colleagues argues that those interactions with the healthcare system are shaped by the family's socioeconomic position (2017, pp. 7). Literature also argues that the combination of various social characteristics and how those characteristics interact with the present medical system can influence healthcare accessibility and, in turn, impact their physical health and health outcomes (Levesque et al. 2013, pp. 6). Health status is not solely biological

[2] My research focusses on access to psychosocial care for AYA cancer survivors. Understanding how language barriers can affect access to healthcare to the general population offers a starting point to studying a potential parallel between healthcare and psychosocial care accessibility, and the general population and AYA survivor population.

but also influenced by sociodemographic characteristics, such as income, age, education, ethnicity, and immigration status (Levesque et al. 2013, pp. 6), and potentially by the presence of language barriers, which I explore in this thesis.

Social and Health Demographics of Canadian Cancer Survivors—A Subpopulation:

A prior study on the social determinants of health on general populations questioned whether health could be impacted by social or economic capital, or rather by an interaction of both factors (Ahnquist et al. 2012). This study shows that each characteristic has an independent impact on health outcomes. Low capital, whether social or economic, has a negative impact on health. In addition, their interaction often increases the scope of their impact (2012, pp. 935).

Other studies emphasize the importance of a subgroup categorization to a limited extent. For example, a study on social outcomes among pediatric cancer survivors focuses on their social position in conjunction with their diagnosis and examines how these may affect their lifetime progress in attaining social and professional milestones (Gurney et al. 2009). The study reports that pediatric leukemia survivors tend to have a larger marital status disparity compared to those who have never had cancer, even when considering societal shifts in marital status (2009, pp. 2393). The study goes as far as pointing out that marital discrepancies can vary according to the type of diagnosis: "Greater disparities in marital status have been observed in survivors of leukemia. […] Females treated with cranial radiation therapy were at an increased risk of never having been married." (2009, pp. 2393). While this study has a greater focus on pediatric cancer survivors as a population of its own, it focuses on diagnosis as the defining characteristic that impacts their social standing, rather than just a characteristic that is intertwined with other social traits. The argument here is that the cancer diagnosis has more to do with social outcomes than with any other social characteristic of the survivors.

In the same vein, a previous study on the Canadian cancer survivor and patient population was conducted to report sociodemographic characteristics. This study ranged from 2015 and 2018 and analyzed data collected in a population-based survey of cancer survivors in all life stages beginning from adolescence (Zakaria, 2020, pp. 849).

The study by Zakaria (2020) found that there is a larger financial disadvantage among AYA cancer survivors due to more work and education disruption caused by a current diagnosis and treatments. They also point out that health behaviours among "post cancer" survivors, such as smoking and drinking, may create an increased risk when compared to those who have not had a cancer diagnosis in their lives, suggesting a need to address "modifiable health behaviours in young cancer survivors" (2020, pp. 865). This research also points out that those in older age categories with a current cancer diagnosis report lower life satisfaction and mental health status, as well as other chronic conditions, when compared with their non-diagnosed counterparts (2020, pp. 865). It also investigates the differences among age groups, notably adolescents and young adults (15 to 39 years of age), to older adults (above the age of 40)[3]. However, the AYA age group was not able to be properly represented in their analysis of the statistical data available to them at the time, and has not been able to draw any significant claims to their mental health as a population and an age group within the cancer survivor population: "after adjusting for sociodemographic and comorbidities, however, only the likelihood of fair to poor health remained significantly elevated" (2020, pp. 853). The lack of insight among both age groups demonstrates a gap in the literature on mental health characteristics of AYA cancer survivors in Canada.

[3] While I am interested in how this study treats heterogeneity among age groups, I should note that it engages with a broader age range than my study did. For feasibility, I focused on participants aged 18 and up, though I did ask them about their adolescent and young adult experiences.

This report also states that those who have had a cancer diagnosis report a significantly higher instance of having a regular healthcare provider than those who have never had a cancer diagnosis. It is also pointing out that this disparity is still observable even as the survivors move onto long-term remission, albeit to a lesser degree than when they were in active treatment (2020, pp. 865–866). This notion suggests improved access for cancer survivors in comparison to Canadians who have never had a cancer diagnosis. It may be important to point out that this might also be cyclical. In other words, if someone is getting a cancer diagnosis, it is a clear sign that they have already been navigating the medical system and have had access to specialists who were able to offer the diagnosis in the first place. However, this article suggests that a cancer diagnosis opens more doors to accessibility to healthcare providers such as specialists and oncologists. It also states that there are still improvements to be made and many AYA survivors "report unmet physical, emotional and practical concerns" (2020, pp. 866), which demonstrates a lack of knowledge on the needs of this group.

Although this report is a valuable view of healthcare access for the Canadian cancer survivor's population, it is important to note that this literature has focused on comparing those who have had a cancer diagnosis in their lifetime to those to have never had one. While the comparison among those in active treatment and those in long-term remission is extremely valuable, it is also of note that there is no insight into the social and demographic characteristics of the group as a heterogeneous population, apart from an age distinction. For example, there very little information concerning immigrant status, language spoken at home or education. When they do report on educational attainment, there is a focus on cancer diagnosis as the deciding factor.

One study on pediatric survivors' outcomes demonstrates there may be social characteristics among the survivors that can influence the degree to which a cancer diagnosis can impact educational attainment. An article citing several studies "suggests that subgroups of survivors achieve educational outcomes comparable to their peers" (Brinkman et al. 2018, pp. 2192). In addition, there are reports in Europe that show that in some cases survivors achieve higher educational outcomes than those of the general population (2018, pp. 2192).

The studies referenced in this article state that cancer survivors tend to surpass or achieve the expected average educational attainment of people who have never been diagnosed with cancer because of the presence of physical sequelae. Dumas and colleagues explain that physical limitations can lead male survivors to disregard blue-collar employment and opt for white-collar careers, which require post-secondary education, because it is easier on their bodies (2016, pp. 1064–1067).

There seems to be an apparent impact on career choices by the sequelae the survivor faces, and, in consequence, the educational trajectory chosen. However, literature continues to place the diagnosis at the forefront of their social outcomes without considering much more than gender. Social determinants of health may play as much of a role within a subpopulation situation, such as AYA survivors, as it can when studying the entire population of Canada.

As an example, a study based in South Korea demonstrates that there is a difference in mortality when considering socioeconomic status along with the type of diagnosis. The authors cite unequal access to proper healthcare facilities and exposure to potential carcinogens when faced with less-than-desirable living situations due to their economic status (Son et al. 2011, pp. 114). The study also points out that caregivers in a lower income bracket may not be able to

"devote as much time to take care of their children with cancer as compared to more advantaged parents" (2011, pp. 114).

Locally, a similar situation is observable. A study focusing on healthcare access for people living in poverty in Quebec shows evidence that healthcare providers lack an understanding of their living situation, and that the healthcare system lacks the resources to offer accessible care to those who are in need. The study points out that some of the issues in healthcare access might be in relation to the person's "culture, gender, or health literacy level" (Loignon et al., 2015, pp. 9). This report prescribes changes to the medical system that should consider the "social determinants of health, such as poverty, poor housing, and food insecurity" (2015, pp. 9).

A final example I want to highlight is a systematic review of twelve studies on the self-perceived mental health of AYA cancer survivors. It reports that, in seven of the twelve studies it reviewed, young survivors do tend to have lower life satisfaction and mental health. The remaining five studies do not report any significant differences (Tanner et al., 2023, pp.18388). However, the comparison is once again made with adolescents and young adults who have never been diagnosed with cancer. The review does not consider any social variation within the survivors' subgroup itself.

In short, articles that focus on cancer survivorship have no difficulty demonstrating how devastating a cancer diagnosis may be in the lives of young survivors and their future. They show how a diagnosis can negatively impact one's economic status, educational status, and employability. Studies on the general population also show how one's social position can impact their health in the first place. The argument still stands that a similar approach should be made

towards cancer survivors as a heterogeneous subpopulation to continue advancing the knowledge of their specific needs.

Language Barriers and Access:

One of the social characteristics that is of interest when looking at cancer survivors as a population is language. A previous study studying Canada's "Official Language Minorities" (OLM) brought forward some distinctions in accessibility to healthcare. It points out that there is an important shift in the Canadian demographic, where OLMs have become more condensed into the Montreal region, which holds around 80% of that portion of the Canadian population. The study also points out that for someone to be considered an "official language minority" in their study, they must be speaking primarily a different language than that of their residing provinces. In other words, English-speaking Canadians in Quebec and French-speaking Canadians in other provinces would be considered as OLMs in the scope of this study (Ngwakongnwi, 2012, pp. 711). This study finds that "language barriers and socioeconomic disadvantage negatively influence access to healthcare services for linguistic minorities" (2012, pp. 713). It notes that English speakers in Quebec have much lower rates of having a regular medical practitioner than French speakers outside of Quebec would typically have. Initially, this disparity might have been a result of a generally younger English-speaking population in Quebec, in comparison to French Canadians residing in the rest of Canada (2012, pp. 714). However, even after controlling for age, the author finds the same disparities among both groups, which favour French-speaking Canadians in terms of accessibility to care as official language minorities (2012, pp. 714).

However, a second study points out that French-speaking Canadians outside of Quebec "report issues with patient assessment, misdiagnosis, and/or delayed treatment, and limited patient understanding of their health condition or prescribed treatment" (De Moissac & Bowen,

2019, pp. 29). In both studies mentioned, the authors state that language barriers among English- and French-speaking Canadians echo international research on healthcare and language barriers. This shows that those who struggle to speak the language that their healthcare provider is working with often experience issues with diagnosis, treatment, and confidence in their healthcare providers. Previous research in the United States on the impact of language barriers and immigration status of Spanish-speaking caregivers of pediatric patients (Zamora et al., 2016) demonstrates that even for the caregivers of young patients, these social characteristics have an impact on the quality of care their child may receive. This is due to a lack of communication and discrepancies in previous experiences with healthcare between Spanish-speaking and English-speaking patients and caregivers (2016, pp. 2178). It also suggests a larger gap in knowledge and understanding in terms of their child's treatment plan and potential side effects. Spanish-speaking caregivers also experience larger discrepancies in relation to their employment and schooling when having to care for a sick child. Their migrant status can also impact the decision-making process among healthcare professionals and the caregivers themselves (2016, pp. 2178).

Another study echoes this sentiment by demonstrating a lack of confidence with primary healthcare providers (Wong et al., 2014, pp. 12), which is most variable when accounting for ethnicity and whether the participants are English-speaking. Visible minorities who do not mainly speak English reported having less confidence in primary healthcare providers (2014, pp. 12). This is likely caused by improper care and communication from healthcare professionals, which may be attributed to a lack of understanding and effort brought forward by the professional to remain on the same page as the patient. The study explores care experiences by their participants' perceptions of feeling listened to and cared for by their providers, and whether they found their wait time to be acceptable. Despite a general low level of confidence by

visible minority groups in medical professionals, they found that Chinese-speaking patients in BC who were part of the study had an even lower level of confidence in the medical system and the care received, in comparison to the care they received in China (2014, pp. 12). These articles imply that language is an important factor in confident, effective, and accessible medical care, meaning that when the patient and provider clearly understand one another, there is a higher likelihood of obtaining the desired results.

In short, the literature strongly suggests that language barriers can have an impact on accessibility to healthcare and the levels of confidence patients have towards healthcare providers. This is pointed out on the Canadian stage with particular attention to provincial language barriers concerning English- and French-speaking patients. While some of the literature is contradictory when assessing the situation among those who do not speak the provincial official language, but do speak one of the two Canadian official languages, studies do not delve deeply enough into the comparisons of those who do not have knowledge of the official languages of Canada.

The following sections of this chapter will continue to show the need to understand the psychosocial and socioeconomic status of Canadian AYA cancer survivors. And by doing so, it will aim to answer the question of mental health disparities for survivors compared to AYA Canadians who have not had cancer, while studying what social characteristics may impact it within the survivor population. It will also investigate accessibility disparities within the subpopulation of the AYA cancer population in Canada.

Methodology:

Access to the CIQSS:

To answer the questions raised in this chapter, access to raw microdata from the recent Canadian Community Health Survey (CCHS) was needed. An application asking for access to the Quebec Inter-University Center for Social Statistics (QICSS) was filled out and submitted. The process involved a formal project proposal and training sessions to ensure the safety and confidentiality of the respondents' data available to those who are granted access. The initial application was done through a governmental Statistics Canada portal online and was then shared with the Concordia & McGill QICSS laboratory and that of the University of Montreal.

From there, syntax and coding were developed on-site, and statistical manipulations for this project were done on SPSS 29. There was a need to go to the lab for this project due to the specificity of this population and to gain access to more recent CCHS data that had not yet been offered as a public-use microdata file at that point. The available Canadian Community Health Survey public microdata files were unable to meet the needs of this study in terms of representative samples of the population at hand. To maintain the confidentiality of the survey respondents, results that had a cell size of less than five were not allowed to be taken out of the lab. Results were then transferred to an Excel sheet before being vetted by the analyst.

Access to the raw data from within the QICSS allowed the construction of an adequate sample of Canadian cancer survivors aged 18 to 39 years. It also permitted the coding of variables to allow generalizable findings.

What is the Canadian Community Health Survey (CCHS)?

The Canadian Community Health Survey was created by both Statistics Canada and the Canadian Institute for Health Information (CIHI) to bridge information gaps in the Canadian health information system. It is a cross-sectional survey whose questions are meant to shed light on healthcare utilization, health status, and to add to the knowledge of Canadian health determinants (Statistics Canada, 2024). The questions make up "Modules" that cover various themes regarding health status and consultation of the general population that can respond.

Data has been collected every two years from 2001 to 2007, where it was collected yearly from that point on. The questionnaire has been administered to participants online, apart from some interviews conducted by phone, which was the main method prior to the transition to online questionnaires. In any case, the survey is available in both Canadian official languages.

Sampling is stratified by health region and uses two frames: one of the labour force surveys and the other from the census. The targeted population is Canadians over the age of 15 years old, with the exemption of populations living on reserves, incarcerated individuals, and full-time Canadian Armed Forces members, which altogether make up less than three percent of the population (Statistics Canada, 2024).

Creating the Datasets:

Canadian AYA Population Dataset:

To start, the analytical sample of AYA Canadians for my study was achieved by pooling three previous datasets ranging from 2015 to 2020. Select variables were changed to have the same coding and variable names before being pooled into one large dataset. Then simple frequencies were run on SPSS to see whether the pooling of data was done successfully.

After combining the three data files, recoding the age variable into the age group of interest (between 15 and 39 years of age) was possible. This enabled me to restrict the sample size to only include the AYA group this project is interested in (N= 64,143). This became the main dataset for the first part of the statistical manipulations made in SPSS that represented all Canadians in the age group for this study that responded to these surveys. To add a little more context in the analysis, another variable was created dividing the population by age group; "Young adult (20–39)" (N= 46,555) and "Adolescent (18 & 19)" (N= 17,588).

Variable for Cancer Status

Before continuing onto the syntax for the frequencies of the variables, the variable for "Cancer survivors" was created by recoding "Never had Cancer" "Ever Had Cancer" and "Currently Has Cancer" into a dummy coded variable (0= Never Had Cancer, 1= Had Cancer). The recoding created a variable representing all cancer survivors, by combining those who have had cancer and those who currently have cancer under the same label (N= 743), and those who never had cancer (N= 63,400).

Before focusing the analysis on Canadian AYA cancer survivors as a subpopulation, a first part of the analysis focused on the comparison of AYA cancer survivors and AYA Canadians who have not had a cancer diagnosis. This part of the analysis is meant to show the differences that are apparent among the groups, notably in terms of mental health and well-being. It is also meant to demonstrate variations in social demographic characteristics, such as immigrant status, educational attainment, income, language spoken, and visible minority status.

Canadian AYA Cancer Survivor Subpopulation Dataset

For the second part of the analysis, another version of the pooled and age-restricted dataset was created. This time, the second dataset consisted of only AYA who had a cancer diagnosis within their lifetime (n=743). Having a second dataset with only the survivors allowed a more pointed statistical analysis that would show the variations within the population.

Language

Variables such as “knowledge of official language” and “language spoken at home,” which had participants write in their answers, were then simplified into fewer categories. The variable of “knowledge of official languages” was categorized as follows: “English only,” “French only,” “Both English and French” and “Neither” (0= English only, 1= French Only, 2= Both English and French, 3= Neither).

The variable for “language spoken at home” was condensed into three categories: “English,” “French” and “Other” (0= English, 1= French, 2= Other). This was done with the goal of simplifying analysis and viewing the language spoken at home as an additional layer to the contextualization of knowledge of official languages.

Immigration

Country of origin was recoded into a variable on immigration, specifying who was considered “immigrant” or “non-immigrant” in the analytical sample, meaning born in Canada or outside of Canada (0= Non-immigrant, 1= Immigrant). The same was done with the variable that showed the amount of time in Canada, which was categorized as “more than” or “less than” ten years (0= More than ten years, 1= Less than ten years).

Ethnicity

The CCHS has a variable for ethnic background, which includes 13 different categorizations. These categorizations were sorted into two categories: “Visible or Non-visible Minority.” This simplified version became the dummy coded variable defining “Visible Minority” and “Non-visible Minority” (0= Visible, 1= Non-visible Minority). Though it is an overarching term, it allows for analyses to consider the social standing of the participant, while taking into consideration their lived experience as either a visible or non-visible minority in Canada. The CCHS defined visible minorities as per the definition by the Employment Equity Act: “persons other than Aboriginal peoples who are non-Caucasian in race or non-white in colour” (Statistics Canada, 2023).

Income and Education

Household income was originally divided into five categories in the datasets. They were then re-coded into three categories for simplicity. The three categories are meant to show the disparities among lower, middle-, and higher-income Canadians: “Less than $39,999,” “Between $40,000 & $79,000” and “Above $80,000” (0= Less than $39,999, 1= Between $40,000 & $79,999, 2= Above $80,000).

Both the levels of education of the individual respondent and of their households were recoded in the same way respectively. Categories were simplified into three groupings by type of graduation: “Less than secondary school,” “Secondary school, no post-secondary education,” “post-secondary certificate, diploma, or university degree” (0= Less than secondary school, 1= Secondary School but no post-secondary education, 2= post-secondary certificate, diploma or university degree).

Mental Health

Four original variables make up the mental health category for this thesis. “Perceived mental health” was recoded into a dummy variable distinguishing good mental health from poor mental health. Perceived mental health was coded =1 if respondents reported their mental health as excellent, very good, and good and =0 if they reported their mental health as fair or poor. The following three variables quantified having a mood disorder, an anxiety disorder or both. They were all dummy coded as well. The variable for mood disorder was divided into “Does not have a mood disorder” and “Has a mood disorder” (0= Does not have a mood disorder, 1= Has a mood disorder). Anxiety was recoded similarly: “Does not have an anxiety disorder,” “Has an anxiety disorder” (0= Does not have an anxiety disorder, 1= Has an anxiety disorder). The final variable that defines mental health status is having anxiety and a mood disorder at the same time: “No” and “Yes (0= No, 1= Yes).

Healthcare Access

Two variables make up the concept of healthcare access in the scope of this project. The first one is defined as having “consulted a mental health professional” within the last 12 months at the time of each survey. This variable was also dummy coded (0= No, 1=Yes).

The second variable pertains to having a regular provider, meaning there is a specialist or regular physician that has been tasked with the participants’ care. The variable “has a regular provider” is coded in the same way as the previous healthcare accessibility marker.

<u>Statistical Manipulations</u>

Crosstabs

My analysis begins with cross-tabulations. Tables 1 through 6 compare those who have had cancer to those who have never had cancer. It uses the full sample size (N= 64,143) and compares the "Cancer dummy" variable to every other variable of interest pertaining to perceived mental health, mood disorder, anxiety disorder, a combination of both disorders, consultation for mental health in the last twelve months, and descriptive demographic characteristic variables.

These tables were produced to help answer the first sub-question of the chapter, which asks about the disparity among Canadian AYA cancer survivors and those of the same age group who have never had cancer in their lifetime. These analyses were meant to allow a comparison among the two groups to understand whether there is a significant disparity in terms of mental health and healthcare access when accounting for a cancer diagnosis.

From Table 7 until Table 10, the study approaches the analysis the same way as the first six; I use a Chi Square test and a strict confidence interval for studying the significance among each association but focuses solely on the differences among Canadian AYA cancer subpopulation. The analyses were meant to answer the following question: "What social characteristics can affect psychological well-being within the Canadian AYA population?" Variables like "Consulted a mental health professional- 12 months," "immigration status," "knowledge of official languages," "visible minority status," "household income," "Sex," "respondent's level of education," "household education" and "Has a regular provider" were crossed with the four variables on mental health describing perceived mental health and having a

mood disorder (Good perceived mental health, Poor perceived mental health, Has no mood disorder, and Has a mood disorder, Doesn't have a mood disorder).

Logistic Regression

The analysis also employs logistic regression, which looks at the probability of an event occurring based on the binary variables included in the model. The question this section was meant to answer was whether Canadian AYA cancer survivors experience difficulties in healthcare access. It also aimed to see if, within those potential difficulties, language could be impactful as well.

To do so, the first model focused on the social position variables. Those included were; Visible or Non-visible Minority (Reference is "non-visible minority"), Household income under $39,999 (Reference is "Over $40,000"), Household income between $40,000 & $79,999 (Reference is "Other"), Sex (Reference is "Female"), Household having less than a high school education (Reference is "Other"), Household only having a high school education (References "Other"), and immigration status (Reference is "Non-Immigrant"). These variables were included in the model to have an idea of the probability of the impact these characteristics may have on healthcare access, which in the scope of this project is observed through the variables "Having a regular provider" (Reference is "No") and "Consulted in the last twelve months for mental health" (Reference is "No").

The last two models include all the same social characteristic variables that are mentioned above, but each includes one of the two language variables. The first of the two models includes the variable "Language spoken at home—English" (Reference is "Other"). The second model exchanges this variable for "Knowledge of official languages—English"

(Reference is “Other”), allowing the possibility to infer the potential impact language has on healthcare access as is defined in this project.

Results:

Cross-sectional Analyses of Canadian Cancer Survivors with People Who have not had Cancer.

Mental health

Table 1. Canadian AYA population - Descriptive statistics on mental health by cancer status. (N= 64,886)

	Never had cancer in their lifetime		Had cancer in their lifetime		
	N	%	N	%	*p*
Self rated: Good mental health	59109	91.9	613	82.9	
Self rated: Poor mental health	5034	8.1	130	17.1	.000

Table 1 describes the significance of reporting poor self-rated mental health as an AYA Canadian, depending on their cancer status. There appears to be a significant association between cancer status and perceived mental health. Those who have had a cancer diagnosis report more often poor perceived mental health when looking at the adolescent and young adult Canadian population (N=130/743, 17.1% & N= 5034/64143, 8.2%, P .000).

Table 2. Canadian AYA population - Descriptive statistics on anxiety, mood disorder, and anxiety & mood disorder by cancer status. (N= 64,886)

	Never had cancer in their lifetime		Had cancer in their lifetime		
	N	%	N	%	*p*
Does not have anxiety	57163	89.9	556	75.3	
Has anxiety	6980	10.1	187	24.7	.000
Does not have a mood disorder	58633	92.2	580	80.5	
Has a mood disorder	5510	7.8	163	19.5	.000
Does not have anxiety & a mood disorder	60897	95.3	630	86.7	
Has anxiety & a mood disorder	3246	4.7	113	13.3	.000

Table 2 describes the prevalence of having a mood disorder, an anxiety disorder or both simultaneously as an AYA Canadian, depending on their cancer status. When looking at having either a mood disorder or an anxiety disorder, once again cancer patients and survivors report significantly more often to either mood disorder or anxiety disorder (for Mood Disorder: N= 163/743, 19.5% & N= 5510/64143, 7.8%, P .000) (For Anxiety Disorder: N= 187/743, 24.7%, N= 6980/64143, 10.1%, P .000). In addition, those with a cancer diagnosis also report significantly more often that they experience having both an anxiety disorder and a mood disorder, in comparison to their healthy counterparts (N= 113/743, 13.3% & N=3246/64143, 4.7%, p= .000).

Background and Culture:

Table 3. Canadian AYA population - Descriptive statistics on immigration, time in Canada & visible minority status. (N= 64,886)

	Never had cancer in their lifetime		Had cancer in their lifetime		
	N	%	N	%	*p*
Is not an immigrant	53280	76.0	680	88.0	
Is an immigrant	10863	24.0	63	12.0	.000
Living in Canada - More than 10 years	59344	89.9	721	96.7	
Living in Canada - Less than 10 years	4799	10.1	22	3.3	.000
Is not a visible minority	52248	71.5	684	94.0	
Is a visible minority	11895	28.5	59	6.0	.000

Table 3 shows how being an immigrant, residing in Canada for more than ten years, and being a visible minority can intersect with cancer status. Through this dataset, there seems to be significance (p=.000) when looking at immigration status and cancer status. Only 12% (N= 63/743) of survivors are immigrants, in comparison to the 24% (N= 10863/64143) of immigrants within those who have never been diagnosed.

The time since they have arrived in Canada is also significant (p=.000). With 3.3% (N=22/743) of cancer survivors being in the country for less than ten years, compared to 10.2% (N=4799/64143) of those who have never been diagnosed having been in the country for less than ten years, at the time of the survey.

The intersection between cancer status and being a visible minority presents statistical significance in this data. There are significantly fewer minority cancer survivors & patients than the non-visible minority counterparts (N= 59/742, 12.5% & N=11895/64143, 28.5%, p= .000).

Language

Table 4 explores the association statistics of language spoken at home and knowledge of official language by cancer status.

Table 4. Canadian Adolescent and Young Adult Population - Descriptive Statistics on language spoken at home by cancer status. (N= 64,886)

	Never had cancer in their lifetime		Had cancer in their lifetime		
	N	%	N	%	*p*
French	18117	25.5	244	30.6	0.003
English	39465	59.3	468	64.2	0.012
Other	6561	15.3	31	5.2	.000

The language spoken at home also has a significant association with cancer status in these manipulations (p=.000). Speaking French, English or other languages at home seems to have a significant link to cancer status. There seem to be 30.6% of cancer survivors that are solely French-speaking, over 5% than those that do not have a cancer diagnosis (N= 244/743 & N=18117/64143, 25.5%, p= .003). A similar tendency is observable with English-speaking cancer survivors (N=468/743, 64.2% & N= 39465/64143, 59.3%, p= .000). However, there are significantly fewer survivors that speak other languages at home than English and/or French (N= 31/743, 5.2% & N=6561/64143, 15.3%, p= .000). In other words, there is a misrepresentation of families who do not speak the official languages at home as a primary language.

Age and Sex

Table 5. Canadian AYA population - Age group & sex by cancer status (N= 64,886)

	Never had cancer in their lifetime		Had cancer in their lifetime		
	N	%	N	%	*p*
Young adult (20-39)	46555	76.5	680	94.0	
Adolescent (18-19)	17588	23.5	63	6.0	.000
Female	33861	49.9	721	64.4	
Male	30282	58.1	22	35.6	.000

Table 5 shows the cross tabulation of age groups by cancer status. The age group is significant in this data; 94% (N=691/743) of cancer survivors are considered young adults (20 to 39 years of age) in comparison to 76.5% being young adults for non-cancer patients or survivors (N= 46555/64143). Therefore, young adults are disproportionately represented in the cancer survivor group of this sample.

There also appears to be a significant correlation between sex and cancer status within the scope of this study. In the population of those who have never had a diagnosis, males and females are more evenly dispersed. However, within those with a cancer diagnosis, women make up 64.4% (N=529/743, p= .000).

Income and Education

Table 6 shows the how household income and respondents' level of education intersects with cancer status. Having a higher household income seems to be significantly more prevalent among those who have never had a cancer diagnosis. And being in the lower income bracket is prevalent among cancer patients. With 22.3% (N=199/743) of survivors making less than 39 999$ a year versus 16.4% (N=11880/64143) for those who have never had a cancer diagnosis. There is a smaller difference in the middle-income bracket between those who have never had cancer and cancer survivors.

Table 6: Canadian AYA population - Descriptive statistics on household income and respondent's educational attainment by cancer status. (N=64,886)

	Never had cancer in their lifetime		Had cancer in their lifetime		
	N	%	N	%	*p*
Income of less than $39,999 - Household	11880	16.5	199	22.3	
Income between$40,000 & $79,999 - Household	17052	25.5	193	27.4	
Income above $80,000 - Household	35211	58.4	351	50.3	.000
Less than high school diploma - Respondent	17080	21.8	107	11.7	
High school diploma - Respondent	12581	20.6	152	20.4	
Post-Secondary certificate, diploma or university degree - Respondent	34482	57.6	484	68.1	.000

In terms of a respondent's education, having a cancer diagnosis appears to positively impact educational attainment. Cancer survivors report a higher instance of a post-secondary certificate or university degree than their counterparts (N=484/743, 68.1% & N= 34482/64143, 57.6%, p= .000). They also report a lower instance of not having a high school diploma than

others who have never been diagnosed (N= 107/743, 11.7% & N= 17080/64143, 20.6%. *p*= .000).

Cross-sectional Analysis of AYA Canadian Cancer Survivors' Mental Health as a Subpopulation

Background and Culture

Table 7. Canadian AYA cancer survivor population - Perceived mental health, mood disorder by immigrant status and visible minority status. (N=743)

	Good perceived mental health		Poor perceived mental health			Does not have a mood disorder		Has a mood disorder		
	N	%	N	%	p	N	%	N	%	p
Canadian born	561	87.6	119	89.8		585	86.2	155	95.1	
Immigrant	52	12.4	11	10.2	.514	55	13.8	8	4.9	.007
Is not a visible minority	565	88.0	119	85.2		534	87.2	150	88.6	
is a visible minority	48	12.0	11	14.8	.429	48	12.8	13	11.4	.676

Table 7 observes immigration status and visible minority status' intersection with perceived mental health status and mood disorder. For cancer survivors, immigration status appears to have a significant link to the absence of a mood disorder (N=8/163, 4.9% & N=55/580, 13.8%, *p*=.007). Immigrant survivors report less often having a mood disorder than non-immigrants or having both anxiety and a mood disorder as often (N= 5/113, 3.6% & N=58/630, 13.2%, *p*=. 012).

In short, the respondents report significantly less often having both mood and anxiety disorders. However, there does not appear to be any significance when observing the relationship among their level of self-perceived mental health (*p*= .514) and whether they have an anxiety disorder (*p*=.175).

Knowledge of official languages in Canada does not seem to have any significance on a survivor's mental health status according to this sample. Whether we are looking at mood disorders (*p*= .305), anxiety disorders (*p*= .369), both (*p*= .644) or overall perception of mental health (*p*= .764) (Results not shown in table).

Table 8. Canadian AYA cancer survivor population - anxiety disorder, and anxiety & mood disorder by immigrant status and visible minority status. (N=743)

	Does not have an anxiety disorder		Has an anxiety disorder			Does not have a mood & anxiety disorder		Does have a mood & anxiety disorder		
	N	%	N	%	p	N	%	N	%	p
Canadian born	502	86.9	178	91.0		572	86.9	108	96.4	
Immigrant	54	13.1	9	9.0	.175	58	13.2	5	3.6	.012
Is not a visible minority	509	85.7	175	92.9		579	87.0	105	90.5	
is a visible minority	47	14.3	12	7.1	.017	51	13.0	8	9.5	.373

Table 8 looks at the cross tabulation of immigration status and visible minority status with anxiety disorder and having booth a mood and anxiety disorder at the same time. Being a visible minority also does not seem to have any significance on mental health, except when looking at anxiety disorders (*p*= .017). However, survivors who are visible minorities (N=12/743, 7.1%) report significantly less often having an anxiety disorder than survivors who are not visible minorities (N= 47/743, 14.3%).

Demographic Variables

Table 9 looks at age groups and sex of survivors and their associations with their perceived mental health and mood disorder. When looking at the AYA cancer survivor and patient population while considering their age category with mental health variables, there is no significance on whether a survivor reports having any sort of disorder or reporting poor mental health, regardless of whether they are in the adolescent age group or young adult age group.

Table 9. Canadian AYA cancer survivor population - Perceived mental health, mood disorder by sex. (N=743)

	Good perceived mental health		Poor perceived mental health			Does not have a mood disorder		Has a mood disorder		
	N	%	N	%	*p*	N	%	N	%	*p*
Young adults (20-39)	568	93.7	123	95.4		533	93.1	158	97.5	
Adolescents (18-19	45	6.3	7	4.6	.504	47	6.9	5	2.5	.065
Female	430	62.1	99	75.0		392	60.7	137	79.7	
Male	183	37.9	31	25.0	.011	188	39.3	26	20.3	<.001

There is significance when looking at sex and mental health status. The use of the terms male and female is due to the limited data available from the CCHS datasets on gender, leading to the focus on biological sex variables that cannot account for the nuances in gender identity, which is important to take into consideration moving ahead with this section of the table's analysis.

Table 10. Canadian AYA cancer survivor population - anxiety disorder, and anxiety & mood disorder by sex. (N=743)

	Does not have an anxiety disorder		Has an anxiety disorder			Does not have a mood & anxiety disorder		Does have a mood & anxiety disorder		
	N	%	N	%	*p*	N	%	N	%	*p*
Young adults (20-39)	512	93.1	179	96.8		583	93.6	108	96.4	
Adolescents (18-19)	44	6.9	8	3.2	.088	47	6.4	5	3.6	.311
Female	377	59.2	152	80.8		435	62.3	94	78.6	
Male	179	40.8	35	19.2	<.001	195	37.7	19	21.4	.004

Table 10 shows the cross tabulations of age group and sex with anxiety status as well as the presence of mood and anxiety disorder simultaneously. Females report significantly more often having poor mental health than males (N=31/130, 25% & N= 183/613, 37.9%, p= .011). The same significant increase for females is observed in terms of mood disorders (N= 26/163, 20.3% & N= 188/580, 39.3%, p= < .001), anxiety disorders (N= 35/187, 19.2% & N= 179/556, 40.8%, p=< .001), and the combination of the two (N=19/113, 21.4% & N= 195/630, 37.7%, p= .004). In other words, the proportion of females reporting poor mental health and the presence of disorders increases by roughly 20% in the cancer survivor's population when only accounting for sex.

Income & Education

Table 11 describes how income correlates with perceived mental health status and the presence of mood disorders for AYA Canadian cancer survivors. There is likely a significant correlation between household income and mental health characteristics. Survivors who report making an income of less than $39,999 report more often poor perceived mental health (N=

58/130, 38%) than good perceived mental health (N=141/613, 19,1%, p= <.001). Very similar results are reported when looking at having mood disorders (N=78/163, 43.9% & N=121/580, 17.1%, p= < .001). In addition, results were similar when looking at incomes and the presence of an anxiety disorder (N= 73/187, 29.9% & N=126/556, 19.8%, p= .008) and having both disorders at once (N=53/113, 40.5% & N=146/630, 19.4%, p=<.001) (results not shown in table).

Table 11. Canadian AYA cancer survivors - Household income by perceived mental health & mood disorder (N=743)

	Good perceived mental health		Poor perceived mental health			Does not have a mood disorder		Has a mood disorder		
	N	%	N	%	*p*	N	%	N	%	*p*
Income of less than $39,999 - Household	141	19.1	58	38.0		121	17.1	78	43.9	
Income between$40,000 & $79,999 - Household	164	28.4	29	22.2		161	29.3	32	19.5	
Income above $80,000 - Household	308	52.5	43	39.8	<.001	298	53.6	53	36.6	<.001

For those who report having good perceived mental health, there is a significant link to having a higher household income ($80,000 or more) (N= 308/613, 52.5% & N= 43/130, 39.8%, p= <.001). The same tendency is visible when looking at those who report not having a mood disorder and having a higher income (N=298/580, 53.6% & N=53/163, 36.6%, p= <.001). This suggests that people who report a higher income tend to report having better mental health characteristics.

Table 12 shows how mental health status for AYA cancer survivors in Canada can correlate with their level of education. Respondents that reported poor mental health also reported having less than a high school diploma significantly more often (N=74/613, 9.4% &

N=33/130, 20.4%, *p*=< .001) There is a similar pattern with those who report having a mood disorder (N= 68/580, 9.6% & N=39/163, 18%, *p*=, 014).

Table 12. Canadian AYA cancer survivors - Respondents education by perceived mental health & mood disorder (N=743)

	Good perceived mental health		Poor perceived mental health			Does not have a mood disorder		Has a mood disorder		
	N	%	N	%	*p*	N	%	N	%	*p*
Less than high school diploma	74	9.4	33	20.4		68	9.6	39	18.0	
High school diploma	117	19.5	35	25.9		114	19.9	38	23.0	
Post-secondary diploma/certificate/degree	422	71.1	62	53.7	<.001	398	70.5	86	59.0	.014

Conversely, survivors who reported less often having poor mental health also reported having a post-secondary diploma or higher (N=422/613, 71.1% & N=62/130, 53.7%, *p*= <.001). A similar pattern is visible for those who reported not having a mood disorder (N= 398/580, 70.3% & N=86/163, 59%, *p*= .014).

Table 13 looks at perceptions of mental health and the presence of a mood disorder with household level of education. There is a significant link between having poor perceived mental health and living in a household where the highest level of education is less than a high school diploma (N=30/613, 3.4%& N=20/130, 13%, *p*= < .001). A similar pattern is observable with those who report having a mood disorder (N=23/580, 3.1% & N= 27/163, 13.1%, *p*=< .001).

Table 13. Canadian AYA cancer survivors - Household education by perceived mental health & mood disorder (N=743)

	Good perceived mental health		Poor perceived mental health			Does not have a mood disorder		Has a mood disorder		
	N	%	N	%	*p*	N	%	N	%	*p*
Less than high school diploma	30	3.4	20	13.1		23	3.1	27	13.0	
High school diploma	71	9.2	28	20.6		66	8.9	33	20.3	
Post-secondary diploma/certificate/degree	512	87.4	82	66.4	<.001	491	88	103	66.7	<.001

Households where the highest level of education is a post-secondary certificate, diploma or university degree seem to present significant links with mental health status as well. In all cases survivors reporting good perceived mental health tend to report having a post-secondary education significantly more often than those who report poor perceived mental health (N=512/613, 87.4% & N=82/130, 20.4% *p*= <.001). Table 13 also shows that reporting poor perceived mental health also has a positive link with reports of having a high school diploma. Those with poor mental health also report having only a high school education significantly more often than those who report having good perceived mental health (N=71/613, 9.2% & N=28/130, 20.6%, *p*= <.001). Very similar results are visible when looking at the prevalence of having a mood disorder. Respondents that stated not having a mood disorder state significantly more often to having a post-secondary education compared to those reporting having a mood disorder (N=491/580, 88% & N=103/163, 66.7%, *p*=<.001). Those who report having a mood disorder tend to report having less than a high school education significantly more often than respondents stating not having a mood disorder (N23/580, 3.1% & N=27/163, 13%, *p*= <.001).

Logistic Regression Analyses of AYA Canadian Cancer Survivors' Access to Care

Cultural Background

Table 14. Canadian AYA population - Descriptive statistics on Consultation for their mental health in the last 12 months by cancer status. (N= 64,886)

	Never had cancer in their lifetime		Had cancer in their lifetime		
	N	%	N	%	*p*
Has not consulted	51701	81.5	472	63.9	
Has consulted	12442	18.5	271	36.1	.000

When looking back again at the descriptive statistics of this project, there appears to be a significant correlation (*p*= .000) between having a cancer diagnosis and accessing healthcare professionals for their mental health in the last 12 months. Of those who haven't had a cancer diagnosis, 18.4% (N=12442) have consulted in the last twelve months, in comparison to those that have had a cancer diagnosis, of which 36.1% (N=271) have consulted. These results made space for the following logistic regression models presented in table 15.

There are three logistic regression models looking at consultation habits for AYA cancer survivors in Canada. Each model looks at variables describing their access to a regular healthcare provider, and mental health consultations in the last twelve months. The models are comprised of variables describing the social characteristics of a survivor that could impact access to care in this context. The variables representing a survivors' knowledge of the official languages and their language spoken at home are also considered to view the influence linguistics can have on accessibility.

Table 15. Logistic regression models: Healthcare access, healthcare access & knowledge of official languages, and healthcare access & knowledge language spoken at home. (N = 743)

	Having a regular healthcare provider						Consulted for their mental health (12 mo.)					
Models	Model 1		Model 2		Model 3		Model 1		Model 2		Model 3	
	p	or	*p*	or	*p*	or	*p*	or	*p*	or	*p*	or
Constant	<.001	11.776	<.001	7.266	<.001	11.652	.937	.988	.039	.666	.972	.994
Visible minority status (Reference: Not a visible minority)												
Visible minority	.002	.362	.010	.423	.002	.361	.788	.920	.939	1.024	.791	.921
Household income (Reference: Other)												
Less than $39,999	.280	.728	.330	.751	.278	.726	.926	.979	.986	1.004	.928	.979
Income between $40,000 & $79,999	.851	1.055	.895	1.039	.849	1.056	.301	.806	.278	.796	.299	.805
Sex (Reference: Female)												
Male	<.001	.367	<.001	.367	<.001	.367	<.001	.315	<.001	.307	<.001	.315
Household education (Reference: Other)												
Less than high school diploma	.037	.388	.080	.448	.037	.389	.457	1.339	.339	1.470	.459	1.337
High school diploma	.328	.698	.361	.714	.333	.700	.598	.861	.663	.883	.595	.859
Immigration status (Reference: Canadian born)												
Immigrant	.632	.840	.785	.903	.655	.848	<.001	.310	<.001	.307	<.001	.309
Language spoken at home (Reference: Other)												
English	-	-	.001	2.120	-	-	-	-	.002	1.781	-	-
Knowledge of official language (Reference: Other)												
English	-	-	-	-	.910	1.015	-	-	-	-	.937	.992

When looking at the logistic regression model for healthcare access, it seems that visible minority survivors are significantly less likely to have a regular provider than their non-visible minority counterparts (OR=.362, p= .002). There does not appear to be a significant difference when looking at consulting within the last twelve months.

Sex of the survivor also has an impact on access. In this sample, Males are significantly less likely to have a regular provider (OR=.367, p=<.001) or having consulted in the last twelve months for their mental health (OR=.315, p= <.001).

Household education also appears to have a significant link with accessibility. Households with less than a high school diploma are less likely to have a regular provider (OR=.388, p=.037). Having a higher level of education is not significantly associated with having a provider. Neither variables appear to have an impact on consultations in the last twelve months.

Immigrant status does have significance in the likelihood of consulting in the last twelve months. Immigrants are significantly less likely to have consulted for their mental health in the last year (OR ,310 - P <.001).

Analyses Including Language Variables

In the two other models mentioned above, including language variables, there is some statistical significance when looking for a correlation among language variables and access to care.

Interestingly, in the model including knowledge of official languages, there does not appear to be statistical significance in the likelihood of having a regular provider. There also does

not appear to bear the significance of having consulted for their mental health in the last twelve months.

There is, however, significance in the model, including the variables for language spoken at home, observable in table 15.

Those who speak English are over one and a half times as likely to have a regular provider as Canadian survivors that speak any other language at home (OR=1,781, p= .002). They are also over two times as likely to have consulted in the last twelve months for their mental health than their counterparts (OR= 2,120, p=.001).

Discussion

The main question of this chapter was whether viewing cancer survivors as a heterogenous subpopulation was the appropriate step forward in social research. The results have shown that it is valuable to view the group as such. Establishing a clear distinction between AYA cancer survivors and those that have never had a cancer diagnosis was the first step in demonstrating the need for distinction.

AYA Canadian Cancer Survivor Disparities:

To start, there is an evident distinction between AYA Canadians who have never had a cancer diagnosis and those who have. For AYA cancer survivors, young adults make up a great portion of the group, whereas in the general population, the proportion of adolescents versus young adults is much less vast than in the cancer survivor group. The Canadian cancer society often reports that there is an age disparity, but by bringing up the biological aspect of age. Comorbidities do come along more commonly as we age (Canadian Cancer Society, 2023, pp. 14). However, sex could be analyzed differently. Females make up most cancer survivors, though it may be in part explained by the higher prevalence of feminine malignancies, it can also be a result of socialization and varying health habits and literacy, which in women could be indicative of closer attention to physical changes and a higher tendency to consult medical professionals when an issue is noticed (Loignon et al. 2015). In essence, better health habits and emotional socialization can impact diagnostic rates, which may not be reflective of the actual incidence of malignancy.

In addition, household income and educational attainment appear to factor in when looking at the distinctive traits of the population. It has been reported in multiple prior research

that having a higher income can benefit one's health by way of easier access to better housing, food, and healthcare (Ahnquist et al. 2012). This is reflected in the results, as more cancer survivors fall into lower income brackets than their peers and the proportion of higher income households versus lower incomes is much vaster among cancer survivors than the general population.

Another example of a clear-cut distinction among cancer survivors and those who have never had a diagnosis is educational attainment. Interestingly, high educational attainment in survivors seems to replicate results from previous studies in Europe, which state that cancer survivors may well surpass other Canadians in educational attainment (Dumas et al. 2016). However, the population appears to reach both ends of the spectrum, whereas a larger portion of the population reports not having a high school diploma yet likely due to the disruption treatment may have caused in their educational attainment. It is important to note that the age of the group we are studying might also be limiting the reliability of these results. It is possible that many survivors may still be completing their degree requirements, whether it is in high school or postsecondary education. Further research must be conducted to know whether these results on education are due to circumstances related to their age, cancer status, or social status.

These results demonstrate that there are social disparities among the AYA Canadian cancer subpopulation. The reasons behind these rifts are something of value to study. Perhaps a look at which behavioural changes and social habits may bring along those differences in educational attainment could be further studied. However, the point of these comparisons is to clearly demonstrate that there are differences that ought to be considered when considering the future of this subpopulation, and that there is immense value in moving forward with research on cancer survivors as a heterogenous subpopulation.

Psychological Well-Being:

Another interest of this chapter is understanding whether this subpopulation experiences varying needs and differing levels of well-being in accordance with one's social and societal position, both as a general member of society but also as a part of this subpopulation. In effect, one of the issues survivors face at varying levels is changes in their mental health and well-being. Cancer survivors tend to have poorer psychological well-being across the board. They report much lower mental health and having mood disorders and/or anxiety disorders much more frequently than the non-cancer survivor population. They also tend to consult for their mental health at a higher rate than their healthy counterparts, likely due to their already-established relationships with medical professionals in oncology that can refer them to other specialists.

Mental health issues are not evenly dispersed across the group. Immigrant and visible minority cancer survivors, though they make up a smaller portion of this population, have fewer mood disorders or mental health issues than their non-immigrant peers. However, this could also be a symptom of a lack of access to mental healthcare and resources, or a question of cultural belief systems with which the medical system may not respond to.

Another example in the results of differing needs is the disparities within the subpopulation in terms of income and education. Household income and education certainly influence the level of psychological distress a cancer survivor may feel. Higher educational attainment and higher income have shown to significantly improve the likelihood of better psychological health in general. The opposite is true for those who live in lower income and lower education households.

However, low educational attainment of the survivors themselves does not necessarily mean they will have lower mental health. They may still be adolescents and in school themselves and may still be part of a household where income and educational attainment are higher on account of their parents or caregivers. Indeed, prior research shows that pediatric cancer patients had better survival outcomes if they were part of a higher-income and educational attainment household, allowing them easier access to better resources, housing, and care (Son et al. 2011). This again shows that a survivor's well-being is not simply tied to their own income and educational attainment; we also see cross-sectional characteristics that influence the type of resources one may have access to, to enhance their overall well-being by attending to their needs.

Accessibility, Immigrant Status, Visible Minority Status, and Language Barriers:

Accessibility, defined in this project as having access to a regular healthcare provider and having been able to consult within the last twelve months, does vary within the cancer population. Visible minorities, immigrants, males, and low educational attainment survivors all tend to have more difficulty with accessibility, whether it concerns having access to a regular provider or actively consulting for their mental health. This parallels results from prior studies stating that economic and social status can affect access to care when looking at entire populations (Loignon et al. 2015). These findings continue to show that cancer survivors ought to be observed as a subpopulation, given that the gap in accessibility differs drastically among cancer survivors and others who have never had a cancer diagnosis. When comparing both, statistically, cancer survivors have less trouble having access to a regular healthcare provider or consultations for their mental health within the last twelve months. This could be theorized by the fact that they are already heavily enmeshed in the medical system as patients. Nonetheless, the point of these analyses is to show that this does not come close to painting the entire picture.

Visible minority survivors are much less likely to have regular healthcare providers. Language can also have an impact on accessibility within subpopulation. In terms of language barriers, initially, the knowledge of official languages was thought to be more revealing in terms of how it can affect accessibility to care. However, it does not appear to cause issues in this population. This conclusion could potentially be a result of the small proportion of visible minorities in the AYA subpopulation data. The limited sample size may not be the ideal representation of the visible minority AYA cancer survivor population in Canada. There may be some significance that has not been represented in this sample.

However, the language spoken at home does have some impact. In the Canadian AYA cancer survivor population, English-speaking survivors have the most ease of access, both in terms of having a regular provider and in terms of consultation for their mental health in the last year, when compared to those who speak either French or any other language. These results reiterate prior literature stating that English-speaking Canadians report the most ease in communication with medical providers (cf. Ngwakongnwi et al. 2012).

The results showing that English speakers have less difficulty accessing care may be a reflection of literature stating that those who do not speak English tend to have a lack of confidence in healthcare providers. With immigrants and individuals who are visible minorities having a much lower rate of accessibility, it could in part be explained by a view of the Canadian medical system that is influenced by cultural differences between the provider and patient. Cultural differences can cause a lack of trust, which could affect the rates at which an immigrant or visible minority AYA survivor for their health.

To reiterate initial findings, immigrants are less represented in the group of cancer survivors, and even less so if they are recent immigrants in the country. Fewer visible minority

individuals make up the cancer population in comparison. This could be a result of language issues and health literacy of newcomers who have yet to fully establish themselves or struggle to navigate the medical system in Canada, echoing the results of a prior study (Loignon et al. 2015). Interestingly, French-speaking Canadians are much more represented in the survivor population. This is likely not a reflection of cancer rates, but rather of diagnosis rates, meaning there is a possibility that some cancers do go undiagnosed due to the access difficulties caused by language barriers and knowledge of the medical system. There is no proper evidence suggesting that French Canadians are biologically more likely to develop a type of cancer or that immigrants are overall healthier. Rather, this likely shows that knowledge of either French or English can positively impact one's access to care.

To conclude, this chapter has shown that, following the statistical manipulations of data on AYA Canadians, there is a visible difference between those who have had a cancer diagnosis and those who have not. In other words, AYA Canadian cancer survivors are a subpopulation with specific needs due to their diagnosis. When compared to the rest of the AYA population in Canada, cancer survivors in this age group report having lower general well-being when observing variables on their mental health and mood disorders. However, Canadian AYA cancer survivors report fewer unmet healthcare needs and better accessibility to healthcare when compared to other AYAs in Canada.

Current literature on accessibility considers social determinants of health when studying a population. It is important to note that social characteristics, such as income, education, immigration status and visible minority status, can be considered when speaking on access to care for AYA cancer survivors. It has been demonstrated through these results that a parallel can be made within the smaller subpopulation of Canadian cancer survivors.

Results also demonstrated that language could have an impact on access to care, either positively or negatively. Essentially, being an English-speaking AYA survivor significantly improved access, whereas speaking any other language did not show significance in improved access. Results were able to show the impact of language despite the statistical limitations of a small sample population derived from a dataset that was not specifically created for this project. Essentially, these results lend weight to the possibility of a parallel between healthcare accessibility issues and issues that arise in the following chapter on access to programs and psychosocial care.

Chapter 4: Psychosocial Support meant for AYA Canadian Cancer Survivors

Introduction:

The previous chapter demonstrated the importance of thinking about differences within the subpopulation of AYA cancer survivors. Characteristics such as language differences and visible minority status, for instance, are studied in chapter 3, which demonstrated that language could have an impact in accessibility to healthcare. The present chapter explores the ease of access to programs structured with cancer survivors' needs in mind. Language remains a point of interest in this section of the study, as well as the impact of the programs on their mental health and general well-being.

I argue that participating in formal support programs has a varying degree of impact that is dependent on the similarities which are observable by the survivors. I also posit that language does have an impact on how easily accessible programs are, and that language influences whether a survivor may struggle to access such helpful support. In addition, this chapter continues to demonstrate the important amount of knowledge on the subject through its literature review section. This will show just how important having access to these types of services and programs is to the Canadian cancer population. The literature review will also present the foundations and charities of interest in this project, and their common goals as support systems for AYA cancer survivors in Canada.

Afterwards, I present a detailed description of the methodology used to support the findings of this chapter. Nine participants generously took part in the project. Three participants were employees of foundations and charities based in the province of Quebec. The employee participants offered insight on their work and plans at Leucan, The Tip of the Toes Foundation,

and the Quebec Cancer Foundation (QCF). Their contribution will be used as an addition to the available information describing the foundations and the programs they offer.

Then a results section will introduce you to the survivors and entourage participants. This section of the chapter will also present the findings following the interviews with each participant. Lastly the discussion section will analyze the results in relation to the chapter's argument, stating that social support is impactful and that it is not equally accessible when accounting for language.

<u>Literature:</u>

The psychosocial needs of survivors:

As mentioned in the previous chapter, the psychosocial needs of cancer survivors vary by age, which brings forward the need of distinct support in relation to their age group.

Takei and colleagues state that the needs of survivors are distinct from the rest of the population, and it is even more the case with adolescent survivors. Their needs are even more particular than those of pediatric and adult cancer survivors due to the developmental stage they are in: "They must move through mental processes such as establishing self-image and identity, sexual roles, capacity for intimacy, economic and emotional autonomy, and educational career planning while coping with the emotional impact of diagnosis" (Takei et al. 2014, pp. 239). They also point out that cancer survivors often exhibit lower levels of "educational status, employment status, and marital status". Combining these tendencies with the age group mentioned above can only hinder psychosocial development more deeply and affect their lives overall, more so than patients or survivors that are at an age where they have already been well established in these aspects of their lives.

In fact, a previous study has mapped out in what ways the adolescent and young adult cancer survivor population needs to be supported. The first way to do so is by recognizing the importance of the role of peers in the development of age-appropriate relationships and maintaining some of the independence that is lost following a diagnosis at such a young age, where parents often must take a more direct role in the lives of the young, diagnosed individual (D'Agostino et al. 2011, pp. 2331). The same is needed in terms of health information; it needs to be direct, clear, and age appropriate to help the survivor navigate this situation in the best way possible for their future: "Information delivered in an age-appropriate manner is critical in helping AYA learn to cope with their illness [...]. Research indicates that nearly 90% of adults with cancer desire maximal information at each stage of their care from diagnosis to post-treatment." (2011, pp. 2331).

The main point this article brings up is that resources for the concerns that affect this age group are most beneficial in terms of psychosocial care. Resources that provide information about sexuality and fertility, academic and vocational functioning, and finances appear to be most valuable to the age group (2011, p. 2232).

An article written by Hydeman and colleagues (2019) echoes this notion, stating that the adolescent and young adult age group not only have distinct needs during treatment, but also following the end of treatment and well into survivorship. They also point out once more that the AYA age group is unique to the older population in terms of their needs due to the sheer amount of psychosocial and/or personal milestones that happen within the 18 to 39 age range, which our survivors tend to miss or be late to reach (Hydeman et al., 2019, pp. 6). This is also reflected in the priorities that the age group may have at the time of treatments and early remission, pointing out that their concerns are not always aligned with other age groups and that these issues are, in

fact, not addressed as much as they would have hoped for or needed (2019, pp. 6). Issues of interest to this group of survivors include finance, family planning, self-perception, relationships, and physical and cognitive effects: “The lack of communication about these issues with healthcare providers suggests that as survivorship care plans evolve from theoretical documents to standards of care [...] they may be particularly beneficial for AYAs” (2019, pp. 7).

Another study develops the notion that AYA concerns differ from the older age groups due to the importance and normalcy attributed to having a diagnosis at an older age. Fatigue is the most prominent concern for older aged survivors; however, it is normalized in AYA cancer survivors (Jones et al., 2020, pp. 9). Indeed, other physical concerns, such as fertility and hormonal levels, are much more prominent in their needs and concerns than the older age groups (2020, pp. 9).

Cognitive changes are also reported in AYA survivors. These issues are much more studied in the context of pediatric cancer patients or older cancer survivors, given their vulnerability to such changes as they are in an age group that already experiences changes and variations in cognitive abilities. (2020, pp. 9). However, it is reported to be an impactful and important concern for AYA survivors: “Almost half the respondents reported changes to their concentration and/or memory, which is higher than that reported in the older age group, and is of concern given the potential for negative impacts on vocational functioning and employment and education outcomes” (2020, pp.9).

While finances are briefly mentioned in the above two articles demonstrating the unique needs of AYA cancer survivors, the following article delves a little deeper. Mahon and colleagues state that cancer survivors under the age of 35 experience an even larger disproportionate gap in

finances (e.g. “debt level and asset acquisition”) in comparison to those of the same age that have never been diagnosed (Mahon et al., 2023, pp. 183).

Though they found that Canadian AYA cancer survivors report having lower debt than their peers, that is likely due to not having debts like loans and mortgages that are often used to reach certain milestones that the age group expects to reach at that point in their lives. The lack of federal assistance specific to cancer diagnosis needs also likely plays an impact on the disadvantaged financial situation of young cancer survivors in Canada: “The substantial time off that AYA cancer survivors require is often not covered by Employment Insurance sick benefits, which allow a maximum of 15 weeks coverage” (Mahon et al., 2023, pp. 183).

Mahon and colleagues also attempted to show social variation within the cancer population but their work on this point was limited by their sample size. Men and visible minorities were unevenly represented in the sample population, and the researchers were unable to make any meaningful distinctions intersecting gender and ethnicity (2023, pp. 183). They were able to point out, however, that educational attainment within the group did have an impact on the financial status and security of the survivor, despite the overarching “survivor” group having larger financial discrepancies from the rest of the population (2023, pp. 183). This shows the utility of attending to distinct subgroups within the population of survivors. It also suggests the value of having programs that cater to specific sub-groups, as they may benefit recovery and survivorship. Notably when the survivor is part of a younger subgroup of AYAs.

The impact of programs:

There is little literature about the impact support programs have on AYA survivors, whether it is long or short term. However, what is documented is positive; survivors tend to report good outcomes following their participation in programs and activities catering to them.

A lot of the literature focuses on pediatric cancer survivors and their experiences with oncology camps, which are a focus of many of my own participants. Martiniuk and colleagues reported on over a decade of literature on the subject. Much of the early literature states that it has a positive impact on "cancer knowledge, mood, self-concept, empathy, and friendship" (2014, pp. 786). Given the year that this article was published, this shows that a positive impact of oncology camps has already been documented for at least twenty years now, improving issues that have been reported as significant to survivorship and well-being for the AYA cancer survivor population as they age. This report also found that more recent literature states an improved quality of life for survivors following their camp activities, allowing them to find improved independence, despite likely having more overprotective parents than their peers, who have never been diagnosed (2014, pp. 786). The review does point out, however, that survivors tend to need a period of readjustment once they return from their camp experience, back to their regular lives. The study states that they may feel a period of loneliness, missing the friends they made at camp and the feeling of ease within a community that understands their situations. Essentially, Martiniuk and colleagues report an overarching positive reaction to the support offered but point out a need to continue gathering feedback at multiple points in time from the campers, as they move past the readjustment period at their return (2014, pp. 786). This is the type of support that has been sought after in the interviews with our participants.

Much of the impact can be described as instances of social comparison. Meltzer and Rourke explain that there is upwards comparison, where there is a positive outcome from comparing oneself to one's peers in a better situation, offering hope and inspiration. There is also downwards comparison, a coping mechanism where one would compare oneself to someone in a less fortunate situation in the hopes of feeling better in their situation. Meltzer and Rourke also point out that the ones you compare yourself with must be similar enough to not create negative emotions (2005, pp. 306). In terms of AYA cancer survivorship, social comparison is common in the literature. In Martiniuk and colleagues' article, the mention of a period of readjustment implies that there is a need to adjust in the social comparison of peers in their day-to-day lives, which likely have not had a cancer diagnosis and would lead to an uneven comparison. Therefore, survivors can develop negative emotions following such noticeable differences. In fact, Meltzer and Rourke state that "adolescents reported feeling more similar to their camp peers than to their home peers, with this perceived similarity to other adolescents with cancer related to positive psychosocial outcomes" (2005, pp. 311). They point out that while at camp, the participants in their study reported positive emotions linked to self-worth and self-perception but felt a much wider divide between them and their peers at home who have not had a cancer diagnosis. It is important to note, as well, that this tendency was already reported in prior studies to this one that focused on adolescents that were actively in treatment. However, their 2005 article stresses that the notion of social comparison is valuable even after treatments end, since their study cohort is mostly (88%) survivors that are in long-term remission (2005, pp. 311). This strongly suggests that the needs of young cancer patients and survivors do not stop at the point of remission but go on years afterwards. It also points out that the positive impacts of programs

catering to survivors, such as oncology camps, continue to have a positive impact on the survivors and their development following remission.

Barriers to accessibility of programs:

As helpful as programs are for the subpopulation of cancer survivors, there are some barriers that can affect the accessibility and equitable use of these resources. A study by Dulko and colleague's states that the first barrier to providing helpful survivorship care is the lack of knowledge of cancer survivors' issues and concerns in the long term. They argue that more communication on what may be needed down the line would be beneficial in aiding the deployment of the survivorship care plans (2015, pp. 7-8).

While communication between providers and patients appears to have improved, there are still some disparities in access for survivors of culturally and linguistically diverse backgrounds (Kasherman et al. 2023, pp. 2052). In fact, the authors demonstrate that there is variation even among the subgroup of diverse survivors by their backgrounds and by their diagnosis, as the study had "generally been restricted to certain patient populations [...] namely breast cancer survivors in the United States of Spanish-speaking or specific Asian-language speaking backgrounds" (2023, pp. 2071). They have found that the use of a culturally sensitive approach has improved care access and success rates by focusing on language disparities that may be present, but also by taking it a step further by integrating community-based participatory research methods; they propose "A partnership approach to research that equitably involves community members, organizational representatives and researchers in all aspects of the research process" (2023, pp. 2071). In essence, this review shows in depth how linguistic disparities can affect healthcare, but also the accessibility and efficacy of survivorship care. The parallel

between barriers to healthcare and barriers to psychosocial care is somewhat visible in these comparisons, which is a link I will continue to demonstrate in this project.

Another article also implies that the same barriers to accessing healthcare can affect accessing survivorship care for adolescent and young adult survivors, as well as childhood cancer survivors alike (McLoone et al., 2023, pp. 154-155). This article primarily speaks of the issues in terms of geographical location and how it may hinder access to survivorship care for this young age group of cancer survivors. McLoone and colleagues quote the financial difficulties that lie within the logistics of travelling to the location of treatment or care, as well as the difficulties that come from “navigating personal and social challenges [...]. These survivors have also expressed the necessity for developmentally appropriate care that recognizes their need for autonomy” (2023, pp. 170-171). While the authors point out the immediate difficulties related to geographical location, it is important to also understand that there is an economic disadvantage at play. Possibly someone may not be able to afford to move to a different location or even commute to the location where the specialized care is offered. They may also have difficulties having time off work to receive the post-treatment support that caters to their age group specifically. Though the intersectionality of income and location is implied in the article, the analysis could be deepened by incorporating the effect that ethnic and linguistic backgrounds could have on accessibility, as has been touched on in the Kasherman et al. article discussed above.

In a study by Blundell and colleagues that examines factors that can influence a family's decision to have their child participate in a pediatric oncology camp, concerns on travel costs, distance from home and difficulty trusting the medical staff on site contributed to issues in accessibility (2023, pp. 3-4). Essentially, the key concerns highlighted in Blundell et al.’s

research are geographical barriers, patient and parent anxiety about being far from home, and "not knowing what camp entailed and wanting to ensure that their [children] would receive proper care," (2023, pp. 3). They explain that a family's hesitancy about participating in an oncology camp is often based on concerns for their child's safety. The main method that was prescribed in this article to reassure families is communication with trusted practitioners (2023, pp. 4-5). Once again, though well-meaning and likely a partially effective remedy in these situations, there may be further barriers—including linguistic barriers—that need to be addressed. These additional barriers may require more structural remedies, extending beyond what can be resolved through trusted communication with practitioners. Though Blundell and colleagues have an interest in a younger age group than that of interest in this thesis, the parents' concerns are not that far from the concerns of young adults, adolescents, or their own parents as well.

The literature can demonstrate that there are buffers to the issues that a survivor may face following diagnosis and remission, but they struggle to delve deeper into the barriers to support. The studies discussed above often state that communication is the key to increased accessibility when communication is likely to have its own barriers that may well be even more difficult for the patient or survivor to surpass.

Local Foundations and their programs:

After a look into the literature exploring the impact of care and the barriers that could affect accessibility to these helpful programs and services, the following section will delve into the foundations and charities of interest in this thesis.

Fondation Québécoise du Cancer (FQC):

Founded in 1979 by five oncologists, the Fondation Quebecoise du Cancer (FQC) dedicates their time and funds to the support of thousands of Quebecois people that have been affected by a cancer diagnosis.

They do so by offering complimentary therapy across the province, and by providing support for the physical and psychological changes that ensue from the diagnosis. The FQC also has affordable temporary housing near hospitals to accommodate patients that would otherwise be unable to travel the distance for treatments (FQC, 2025). There are six different locations across Quebec, all within a short distance of a major hospital offering care and services to oncology patients. At these locations, other patients and survivors can enjoy massage therapy, art therapy, and the services of a kinesiologist (FQC, 2025).

The foundation also offers financial and legal help to those that are in a vulnerable situation. Two years of financial support of up to $1000 yearly is allotted to survivors that fall under the poverty line. Afterwards legal advice is also available, in partnership with *Juripop*, to help survivors navigate any legal procedures that touch the subjects of civil rights, family rights, housing, and laws on succession (FQC, 2025).

The FQC also offers all the same services with particular attention for those who are in the adolescent and young adult age group. They also offer access to counselling and information that is age specific, whether in the AYA age group or older (FQC, 2025).

Leucan:

Leucan is an association for children with cancer based in Montreal, QC, with offices across the province. It has been in operation for over 45 years, supporting clinical research for

pediatric oncology, as well as supporting the families of sick children in the province of Quebec: "The Association provides a number of specialized services: personal assistance, emotional support, financial aid, referral services, massage therapy, playroom staff, socio-recreational activities, the Leucan Information Centre, school awareness programs and support, palliative care support and bereavement follow-up." (Leucan, 2025).

The program they offer that is the most prominent in the context of this study is their oncology camps. The largest event for families supported by Leucan, the yearly summer camp is funded by the *Confédération des Syndicats Nationaux* (CSN). It allows the entire immediate family of the child to attend a week of activities, while having trained volunteers and medical professionals there to ensure a safe and enjoyable environment.

Leucan also has activities and support dedicated to adolescents aged 12 to 17 years old. They offer individual support in the form of counselling, as well as shorter seasonal weekend camps that not only cater to the needs of pediatric oncology, but also to the specific needs of adolescents living with the impacts of cancer diagnoses (Leucan, 2025).

Fondation Virage:

Founded in 1987 and currently based out of the CHUM (*Centre Hospitalier de l'Université de Montréal*), Virage offers activities and programs that echo those of the FQC. The foundation has professional massage therapists and kinesiologists at their disposal to help Quebecois patients beginning at diagnosis. The foundation also offers informational sessions that touch subjects that affect this group, providing counselling on health anxiety, support groups for specific cancers, and information for newly diagnosed people and their loved ones. Virage Foundation also offers services at a preferential price for those who have had a cancer diagnosis.

The service offered includes activities such as cosmetic advice tailored to patients, haircuts and hair piece rentals, and clothing meant for postoperative cancer patients (Fondation Virage, 2025).

Tip of the Toes Foundation/ Sur la Pointe des Pieds:

Founded in 1996 and currently based in Chicoutimi, QC, the Tip of the Toes Foundation offers therapeutic adventure expeditions to young cancer survivors across Canada. These expeditions are made to offer survivors an opportunity to surpass their physical limitations that are often more rigid following a cancer diagnosis. It also allows the young survivor to live a unique experience surrounded by nature and people like them, who have also lived through a cancer diagnosis at a young age. The aim is to improve one's well-being and confidence, as they surpass what they thought their physical and emotional capabilities have become post-cancer (Sur la Pointe des Pieds, 2025).

These expeditions are free of charge to the participants, and the itineraries are shaped in accordance with the groups' capabilities while still presenting a welcome challenge. Groups are typically around 10 to 15 people and organized according to age. The destinations and type of expeditions vary. All located in Canada, many are voyageur canoe trips, some are dog sledding expeditions, and others are a combination of other outdoor activities such as hiking, biking, and kayaking. All the materials for these trips are provided to the participants; they simply need to be present in the activity and enjoy the group setting (Tip of the Toes Foundation, 2025)

These foundations all have a goal, in common, to improve the wellbeing of Canadian cancer survivors. Though some methods are similar, there may be variability in access to these programs. The following section dives deeper in the role language may have in access to

programs such as oncology camps and resources offered to the survivors. Many of the programs that have been mentioned by our participants have not been touched upon in the literature review of this thesis. Oncology camps have been touched on in articles, but closely in relation to the pediatric survivor as a child still. In the case of our participants, those who have been "campers" have reflected on their experience from their perception as a member of the AYA age group.

Methodology:

Research design:

The following section will describe the qualitative methodology of this thesis. Ethical approval was obtained by Concordia University (Project # 30019985). Following established standards, I took steps to assure the participant's informed consent, their confidentiality, and the protection of data that is gathered through the course of this research.

Data Collection:

The data was collected through confidential interviews with each participant. The interviews took place online via Zoom. Every participant had the option to either speak to me remotely or in person, but in all cases the remote option was preferred. With their consent, interviews were audio recorded and then transcribed for ease of analysis.

Participants:

There are three types of participants that were interviewed for this project: Survivors, entourage, and employees. Each participant offered their own perspective to the subject matter of this chapter and thesis.

Select foundations and charities were contacted for this project in the hopes of having a recruitment poster broadcast on their social media, website or newsletter meant to inform potential survivors and entourage participants of the project. The foundations and charities who had an interest in being part of the interviews, and that fit the criteria, were then invited to contact me by email. Emails were also sent to the same foundations inquiring about potential employee participants. I was then referred to the individuals that were open to being interviewed and given their professional contact information to provide more information and scheduling options.

Survivors/Patients:

I sought survivors and participants, who were between the ages of 18 and 39 that had a pediatric cancer diagnosis between the ages of 0 to 39 years, to participate in this study. Selected participants must also have been treated for their cancer diagnosis in Canada and have participated in some form of support program available to them as cancer patients or survivors. Programs such as oncology camps will also have been held within the province of Quebec or organized by a foundation or charity based in Quebec.

Entourage

This category of participants consists of a close member of the survivor or patients' entourage. This category of participant can be defined as either legal guardians, siblings, and/or friends who have had a significant and long-standing relationship and have had some sort of involvement in the programs the survivors have been a part of. Their involvement can be described as the person responsible for signing them up in the activities or being present at the activities along with the survivor.

Employees:

The final type of participant is the employee. This person is either currently or recently has been employed at the foundations, non-profits, or charity organizations that cater to this group of young survivors and their families. They must be a key part of the process and have significant roles in the planning and execution of these programs.

A further inclusion criterion was that participants needed to answer the interview questions in either English or French, regardless of their first language. This limitation is due to a lack of personal knowledge of all the participants' languages spoken at home, as well as a lack of resources to be able to have interviewers that can conduct interviews in participants' first languages.

As mentioned previously, nine participants were interviewed. Three participants were in the Employee category. The remaining six participants were in the Survivors/Patients category (n=5) and Entourage category (n=1).

Data Preparation and Analysis:

Following each interview, the recordings were transcribed verbatim. Initial themes were colour coded and categorized per the research questions they were best fit to answer. Each interview transcript was revised multiple times and listened to during the revision to identify patterns and insights that were both useful in answering the research questions, but also to see if there were any unanticipated findings. Analysis of transcripts was repeated until a thorough understanding of expected and emergent themes was achieved.

In this lens, the results were then categorized not only by questions and themes, but by the participant as well. This is because it is a smaller sample size of survivor and entourage

respondents, and each member of this cohort has experiences that differ from one another, despite all having participated in programs and activities catering to AYA cancer survivors and their family members.

In the following section, themes and patterns are going to be presented in subsections. Under each subsection the survivor and entourage participants' insights will be presented individually. I am presenting the data in this way to preserve participants' unique experiences and to highlight the value and weight of the data they shared. After presenting data from the Survivors/Patients and Entourage categories, I will similarly present data from the employee category.

Results:

Participant Background:

This section presents all six of the participants in this study that have benefitted from any sort of psychosocial support program that caters to AYA cancer survivors and entourage. It also briefly presents the programs they have accessed.

All names have been changed for confidentiality.

David

Now a young man in his late twenties, he was diagnosed with blood cancer in his adolescence. He is a first-generation immigrant of Jewish faith and culture and has obtained post-secondary degrees. He speaks four different languages, including French and English fluently. David was diagnosed while in high school at the beginning of summer vacation. During his treatment he was able to benefit from support by Leucan, offering gift bags with items meant

to improve comfort during chemotherapy sessions. He was also able to benefit from in-hospital massage therapy, which was also provided by Leucan.

Following his remission, David continued to have a relationship with Leucan. Initially his relationship was that of a member of the Leucan teenage support group. Later, it was as a volunteer who had aged out of their services.

David has also benefitted from an expedition offered to him by the Tip of the Toe's foundation.

Gabriel

Gabriel is an entourage participant who is also a young man in his late twenties and a first-generation immigrant. This participant is of a South American background and has a post-secondary education. He also speaks and understands multiple languages: French, English, and Spanish are the three main ones. His younger sister was roughly 11 at diagnosis and passed away in 2010. At the time he was fifteen and had to care for his younger baby brother while his parents were having to handle the responsibilities of having a sick child, and then during their grieving period. Gabriel was able to participate in the Leucan "fall" and "winter" oncology camps despite not being a cancer survivor. He was also able to benefit from a few one-day activities, also provided by Leucan.

Audrey

Audrey is a young French-Canadian woman in her twenties with a post-secondary education. She considers herself bilingual but with more ease in French. She was diagnosed at twelve years old, right as she started high school, with a brain tumour that affected her

progression and integration in high school. Her diagnosis and treatments have caused many physical issues as well that she still works through today.

Audrey was part of Leucan as a camper and as a volunteer later. She was present at fall, winter, and summer camps. She has participated in a nature expedition in Alberta with the Tip of the Toes Foundation.

Lastly, Audrey had gotten resources from *Vous Offrir du Bonheur pour Oublier votre Cancer* VOBOC and Virage foundation (based in the CHUM), where she was offered aesthetic services (massage, wigs, and comfort items during treatments). Audrey also benefitted from support groups, happy hour events and suppers for survivors to spend time together and share their experiences.

Maria

Maria is a woman in her early thirties of European and South American heritage. She is also a post-secondary graduate and has a family. This participant was a new immigrant from France when she was diagnosed with a brain tumour and had to have private health insurance given her citizenship status. She had to pay from her own pocket for the consultation and then have it reimbursed by insurance, which was often disputed.

Having a diagnosis only two months after arriving here from France had stopped her life for a significant amount of time. She had the support of her partner and family to handle a lot of the financial impacts.

Maria had received short-term support during her treatments with the Fondation Virage, based in Montreal's CHUM, which included massage therapy, aesthetic advice, and yoga classes.

She also mentioned VOBOC, which offered her a bag with accessories, telephone support, and advice for young adults with cancer.

Dan

This participant is 39 years old and Canadian born. He speaks English primarily and would describe his French-speaking capabilities as "broken" but functional.

The main disruptions this participant spoke of were the subsequent sequelae that developed caused by a malignant brain tumour diagnosis during his adolescence. He specifically emphasizes how the negative effect it had on his memory is what has impacted his life the most. Dan states that everything must be written down for him to retain. If he plans to attend an event, he must have it in his calendar otherwise it is forgotten.

Dan was a participant with the Make a Wish Foundation and with the Tip of the Toes Foundation. Make a Wish had given him the electronics needed for filmmaking (laptop & software) and the Tip of the Toes Foundation provided a hiking and camping expedition in the early 2000s.

Olivia

A French-Canadian woman in her early thirties, Olivia is only fluent in French and has limited comfort in speaking English, though she does understand it well. Olivia has also completed post-secondary education. She was diagnosed with a form of breast cancer in early pregnancy.

Olivia had participated in activities offered by Le Virage & "Cancer Transition" with the *Organisation Quebecoise des Personnes Atteintes du Cancer* (OQPAC), which is based in

Quebec City and closer to her home. “Cancer Transition” is a hybrid class offered to those newly in remission, offering them tools and advice on how to return to their new normal lives. It offers advice on nutrition and physical health, return to work, and mental health, and gives information on Facebook groups that would serve as support groups for the survivors involved.

Programs Accessed and their Impact:

Each participant, whether they were a family member or a survivor themselves, expressed some positive impact stemming from the support they received, provided by the programs they accessed. Most participants spoke highly of activities offered by either Leucan or The Tip of the Toes Foundation. Other participants have also mentioned short-term activities that have positively impacted them as well.

In nearly all cases, the participants were able to benefit from multiple foundations. Three main themes came up throughout the interviewing process when it pertained to the impact of these programs: a sense of community, personal development, and a new sense of normalcy.

Sense of Community

Nearly all participants reported feeling a sense of community and belonging when taking part in the activities offered to them. In some cases, it was the only way they could feel a sense of community, since, in the hospital setting, they were not guaranteed to be around other patients in their age group.

In fact, during her treatments, Olivia was mostly surrounded by older patients and felt alone in the situation, as she could not find much common ground with them other than their diagnosis. Participating in a nature expedition with the Tip of the Toes Foundation allowed her to be surrounded by people her age that have been through something similar. This broke some of

the isolation and loneliness that she experienced during active treatment despite a slight initial language barrier.

> *"J'ai rencontré vraiment des belles personnes puis ça m'a vraiment fait du bien parce que je me sentais vraiment seule…tout le monde que je rencontrais c'étaient des gens au-dessus de 65 ans dans les salles de traitements et dans les salles d'attente… il n'y avait personne de mon âge. J'avais vraiment besoin d'en parler… puis parler à tes proches… tu sais ils veulent comprendre et ils sont empathiques, mais c'est pas pareil que de parler à quelqu'un qui vit la même chose et qui a les mêmes peurs" (42:58).*

Being around other patients and survivors is often not enough to feel supported. It can even have the opposite effect, as Olivia describes. A young patient is likely to be less lonely among peers, but if the only other patients around them are much older, it can exacerbate negative feelings, feelings of isolation and fear. Olivia's words underscore that a cancer diagnosis at a young age is relatively less common than having a diagnosis at an old age, and the comparison can lead to a negative emotional response to a patient's situation.

Interestingly, cancer status might not be the deciding factor in the matter. Gabriel was able to participate in the Leucan "fall" and "winter" oncology camps despite not being a cancer patient. These weekend long camps had an overall positive impact on him. In general, he felt that it was helpful for him to go to camps hosted by Leucan. It offered a chance to change his perspective and distract himself from his grief and day-to-day responsibilities: *"On a quand même passé des moments pas facile, donc quitter la maison un peu… je me sentais plus comme visible [...] J'avais hâte à la prochaine activité"(Gabriel, 11:54)* Being surrounded by other people his own age, who understand as a group what effect a pediatric cancer diagnosis can have on the family unit, is what was unifying for this participant. Community was not based on his

cancer status, as he was not the one diagnosed, but proximity to the situation and spending time with people in his age group, without the pressures of having to explain the nuances of a cancer diagnosis, are what was the most beneficial in terms of community and belonging.

Gabriel also pointed out that Leucan helped him in terms of empathy, and he had also continued as a volunteer. Audrey and David also continued being volunteers once they had grown out of the services offered by Leucan. Interestingly, both had also participated in separate nature expeditions with Tip of the Toes Foundation as well and mentioned recognizing some of the participants and already having an established friendship with them from their time in Leucan. So, in that sense, Leucan and Tip of the Toes Foundation do create a long-lasting community, which transcends the time-delimited activities that people participate in.

Short form activities offered fewer opportunities to create a sense of community, but it was not impossible. Maria had received short-term support during her treatments with Fondation Virage, which is based in Montreal's CHUM and includes massage therapy, aesthetic advice, and yoga classes. She also mentioned VOBOC[4], which offers a bag with accessories, telephone support, and advice for young adults with cancer. However, she stated that she had a different experience with support. Though Maria claims it is overall a positive thing, she did not feel like their illness defined them enough to need more in-depth support: *"Ce qui ressort c'est le sentiment d'être soutenue, d'avoir des outils accessible pour se sentir moins seule avec tout ça" (Maria, 22:25)*. For this participant, the feeling of having support readily available to her was

[4] Venturing Out Beyond Our Cancer is a not-for-profit charitable organization that offers newly diagnosed AYA cancer patients free resources, tools, and diversion to ease the cancer journey for young survivors in the greater Montreal area (VOBOC, 2025)

enough to improve her general well-being. She felt less alone in the whole ordeal and was able to make a distinction among her self-perception and the illness she was diagnosed with:

"Appartenance n'est pas forcément le bon mot car ma maladie ne me définit pas, mais de communauté… de soutien" (Maria, 23:45). She explains that the presence of support and of a community was what was more poignant to her, and not the notion of belonging to a group of "survivors."

The availability of support and knowing that it is there for her if needed were helpful. She stated that she had enough comfort in knowing that she was not alone and did not want to further define herself by the cancer diagnosis. She found much more support with family. However, the impact of the availability of support is long lasting. The confidence of a "safety net" gave her to move forward in her survivorship is something that she will not forget: "Je *ne peux pas nier que j'y penses encore, évidemment…[...] en fait je pense que ça seras toujours dans un coin de ma tête!"* (Maria, 36:30). There are traumatic experiences and emotions that stay with cancer survivors following their diagnosis, even with the adequate amount of support. It is imperative to have support readily available so that the person who needs it or wants it can access it.

Olivia is also an example of minimal short form intervention because she lives in an area that makes it more difficult to take part in activities in person. In her case, much of the short form activities she could take part in were online. The support and sense of community were still present for her despite it being online. Despite the online accommodation, Olivia stated that support was most impactful when she was able to experience that community in person during a nature expedition.

In any case, there is no denying the pervasiveness of a cancer diagnosis in one's personal view of themselves. There are always moments where the memory of the experience creeps up on a person. Support must be readily available even though not everyone needs or has the same type or the same amount of support. Survivors who do need support benefit from any kind of support.

Personal Development

There was one case where a brief involvement of a charity was able to drastically impact a participants' personal development. The Make-a-Wish Foundation helped Dan move forward with a passion for filmmaking that turned into a career for them: *"They worked very hard, and they got me an amazing laptop and all the software and hardware that I needed. And that springboarded my way into [my career]" (Dan, 20:30).* Here it is clear that even a short encounter with a foundation can drastically affect a Survivor/Patient's development.

However, following discussions with this group, more immersive activities such as camps or nature expeditions have a stronger impact on personal development. In each case, survivors spoke highly of their development from their involvement.

The Tip of the Toes Foundation was an important player in the personal development of participants. David had expressed that it had been helpful for them to develop more of their language skills along with other English-speaking survivors that were in their group. The nature expedition activity was a unique experience that had positively impacted this participant's well-being.

“Dans le temps, mon anglais n'était vraiment pas super. Donc le fait de connecter avec d’autre monde du Canada qui parlent anglais, ça aidait beaucoup à la communication pour l’anglais en tant que tel. Mais aussi pour voir comment les autres personnes dans le Canada ont vécu leur diagnostic, et plus avoir du fun et expérimenter quelque chose de nouveau.” (David, 13:59)

David expressed that the English-speaking skills that were developed during his time with the foundations were useful in his academic endeavours and professional opportunities. The activities also allowed him to have meaningful exchanges with other survivors in Canada, which broadened his horizons.

Dan had mainly spoken about his time with the Tip of the Toes foundation and how the expedition has helped him spiritually. He states that the effort that had to be put into participating showed him what he was, in fact, capable of. The nature expedition has helped him overcome the fears and concerns of what he would be capable of doing, but also in terms of health anxiety.

“Sur La Pointe des Pieds absolutely changed my life for the better. I think about them every day, and I would not be where I am today without them. [...] They gave me the mental strength to overcome all the things that I had been questioning about what I could and couldn’t do. And how to deal with it, and who to talk to [...] They touched on so many of my fears and concerns without ever formally addressing it. We just casually talked about it. We overcame so much… I overcame so much!” (Dan, 23:00).

Dan is expressing how much personal development he had simply by being around other people his age that have experienced what he has. He explains that it allowed him to reach out confidently to his peers and build the skills necessary to ask for the help and support he may

need. The newfound confidence was a tool that he expressed was useful in his future when speaking on personal and professional relationships.

Similarly, Olivia recounts an improvement in confidence in her capabilities. Much like Dan, who had developed confidence in his emotional capabilities, the nature expedition improved on Olivia's confidence in her capacity to return to work post-treatment. Participating in a nature expedition helped her move past the emotional fatigue from treatment and being constantly in the mental state of "I am sick, I need to heal." The experience with the Tip of the Toes Foundation gave her more confidence for her return to work after treatments ended: *"Quand je suis revenue, je me suis sentie plus prête, plus détendue, et plus proche de mon retour au travail [...] je sentais que j'étais plus proche de mon objectif" (Olivia, 36:00).* Olivia also said that her group during the expedition happened to be an all-women's group. She explained that she felt she would not have made as deep of a connection or felt as empowered had it not been the group of people she was placed with for the trip. This empowerment led to Olivia taking the next steps towards her goal of normalcy by returning to work.

For some, personal development happened when they were allowed the time and space to grieve. When Gabriel started as a camper at Leucan shortly following his sibling's passing, there were some frustrations and difficulties fitting in, as there was a bullying situation on his French-speaking abilities and their South American origins.

"Il y avait des moments où je ne me sentais pas à la bonne place. Pas à cause de l'organisation, mais par rapport à moi-même. [...] J'avais un peu de la misère en français dont certains gens parlaient moins avec moi… [...] Mais comme je n'ai pas pu vivre mon deuil, je pense que j'avais de la frustration et peut-être je me retirais plus. Je voulais être un peu seul peut-être?" (Gabriel 8:48)

Bereaved participants at the camp were not common either, likely making it even more difficult for Gabriel to feel as though he were part of the group. Gabriel now feels that there was a positive impact to being at camp, despite the situation with other campers that only spoke French. Leucan activities were helpful for him to manage emotions that his family could not help with, given their own grief. Once everyone started to feel a little more like themselves and were emotionally present for one another, there was less of a need for the support of foundations for Gabriel. In essence, Leucan offered some semblance of normalcy while his home life was going through a drastic change.

Normalcy

Multiple participants expressed that the foundations and charities that offered support were instrumental in creating a sense of normalcy. The feeling of normalcy was reported more often during long-term activities, such as the nature expedition. Participants report feeling "like everyone else" since they were no longer the only person having experienced a cancer diagnosis. For example David stated that being surrounded by other young people that have experienced a cancer diagnosis allowed them to "step out of their own cancer bubble and step away from some medical anxiety.

Audrey had an extremely similar sentiment when speaking of the Leucan camps, and of the nature expedition she has experienced: *"Oui la maladie est toujours la… mais on le vie comme c'est correct et on est tous là dans le même bateau" (11:16)*. Audrey also felt that being with a group of other young survivors cuts stressors lets you live in the moment because you are surrounded by like-minded people that understand your struggles and experiences. Participating allows you to forget your current issues in life, whether they are related to your illness or not. Audrey stated that it helped them move past the embarrassment of their sequelae:

"Ça te fait faire face à des situations que tu ne connais pas. Comme ça tu peux surmonter des défis… [...] Ça te coupe du monde extérieur, ça te fait penser au moment présent. T'as pas à réfléchir à l'extérieur qui est souvent stressant et tu vis avec du monde qui sont dans ta situation et qui peuvent te comprendre. Tout est là pour l'entraide." (Audrey, 10:25)

It appears that being in this kind of environment offers survivors' respite from the stressors caused by their diagnosis and the stage in life they are in. It allows survivors to see how things are with other survivors and not feel that they stand out from the crowd. Their new experiences also allow them to develop the confidence needed to move forward upon their return to their daily lives.

Conversely, despite appreciating being surrounded by women having very similar lived experiences, Olivia appreciated the quiet that a nature expedition can offer.

"Ça l'a été un point de bascule vers la vie normale… ça l'a été vraiment un moment qui a fait du bien [...] Ça te permet de décrocher et vivre dans la nature. On avait des moments seule aussi pour contempler." (Olivia, 35:00)

A calm natural environment was needed to contemplate and think through the experiences they have had. Such an environment would not have been as easily achievable without the intervention of the foundation. It is important to note that being around peers with a similar lived experience was also involved in the comfort of the environment, even when they are taking some time on their own within group activities.

In other cases, short form activities offered the tools needed to move forward with the emotions that have taken precedence. For example, Gabriel expressed a deep appreciation for a

scrapbooking activity meant for families coping with the loss of a loved one, to help them process grief; *"C'est vraiment à cette activité là que j'ai senti que j'avais lâché un poids. [...] Justement ma mère garde toujours le vieux scrapbook de l'activité que j'avais fait." (Gabriel, 18:30).* The figurative weight on his shoulders is what disrupted his normalcy. Gabriel stating that the weight has been lifted shows just how poignant such an activity can be and how it can improve someone's well-being, even with something as simple as a scrapbooking activity organized for a group of people in the same situation.

Language and Access to Programs:

When asked about accessing programs, participants spoke mostly of the signing-up process and the language they most often heard during the programmed activities. Initially there were no obvious claims of issues in access to care. It is important to note that the people spoken to on the matter have all successfully participated in these programs and evidently have not had any major barriers prohibiting them from doing so. However there is insight on what may cause other accessibility issues.

"Signing Up"

Most participants did not point out any difficulties filling out the forms required to participate. All the participants stated that the required documents were available in both French and English. None of them mentioned any translations or even needing one. For returning participants, many foundations offered simplified forms. However, some participants expressed having difficulties with recurring invitations to certain activities and would need to ask charities or foundations for an invitation to an activity they otherwise would not have been invited to

without emailing a request. Their coordinates were given to the foundations, either by participants themselves at their diagnosis, or by a trusted medical professional with their consent.

In fact, a lot of the first contact with any foundation was initiated by the medical team. Oncologists were often quoted to be the ones to share posters of upcoming expeditions with the Tip of the Toes foundation. David even explained that, in a lot of these forms, it was required to have the signature of your oncologist or doctor as a precaution and affirmation that the participants are in good enough health to take part in the activities. He noted that it is much easier for someone to get approval from their oncologist if they were the ones to recommend programs in the first place. Dan had also gotten news of the expedition with the Tip of the Toes foundation from his oncologist, who was also personally involved in the foundation.

Olivia had a similar experience as well, but it was her therapist rather than her oncologist who made the recommendation:

> *"Une psychologue que je voyais m'avait parlé de la pointe des pieds… Ça m'a quand même interpellé ce qu'elle me racontait. Puis le timing etait vraiment bon parce que c'etait au printemps et dans quelques mois il y avait une expédition qui se faisait au réservoir du poisson blanc avec des gens de 30 à 40 ans [...] J'ai envoyé ma candidature puis finalement il y avait eu une annulation et ils ont dit "on peut te prendre"!" (Olivia, 20:20).*

Without the psychologist's advice, she would not have been able to benefit from the foundation's nature expedition program. Like Olivia, many participants speak of their experience with the Tip of the Toes Foundation in a positive and emotional way. They often stated that it was "good timing," as if it was fate that the activity was available to them at the time. This

participant, along with Dan, David, and Audrey, claimed it was luck that their providers suggested their participation with the foundation.

Initial contact is often done by word of mouth between a foundations' representative and the survivors' medical team before it is shared with them. Once the first contact is established, it is at that time that the official documents and information is shared with the potential participant. It is worth noting that, despite the first contact often being word-of-mouth, the rest of the communication is then digital, mainly through emails. Some short form activities, such as those offered by foundations had their sign-up process via the foundation's website, which had limited space. These short activities and the sign-up process were primarily in French. Employees at the hospital were mainly French-speaking as well.

Olivia did point out that there were some polyglot employees available for patients that spoke Spanish, Portuguese, Italian, Arabic, and English. These employees were meant to help with translating at the doctor's office but might have been hard to reach given that they were overall a scarce resource in the hospital and meant for clarifying medical terminology.

Overall, having forms offered in only French or English do not pose an immediate barrier to accessibility to psychosocial care. It is interesting that, in this group, nearly every participant attributed access to any type of support to their oncologists or other members of their medical teams communicating with them, or their parents, on the opportunities. It appears that in these cases, accessing care was much more contingent on their contact with people who were aware of the activities already. There had to be a person between the foundations and charities and the survivors that could relay the services that were available to AYA cancer survivors. The intermediary would, at times, be the encouragement needed to seek the support available to

them. Without the involvement of medical providers, many survivors would not have known where to look for help.

Language Usage on Site

When asking about the forms and sign-up process, many of the participants fluent in French had glossed over the subject, only briefly speaking on the language used in the documents and official correspondence. French-speaking survivors do not delve deeper into the subject, likely because it is nothing of note to them, as they do not notice any struggle understanding or answering the questions posed in the applications.

However, in all cases, there was a brief discussion on the languages spoken by the other survivors and participants in the activities. Dan and Olivia were the most vocal on the subject. Dan is mostly English-speaking, and Olivia is French-speaking. Both struggle a little with the other official language.

For Olivia, language issues were more difficult to overcome. Though formal communications were bilingual, in her group, most of them were anglophone participants with a handful of only French-speaking survivors and some bilingual. This caused informal "cliques," anglophones and francophones in separate subgroups. But Olivia stresses that everything was translated, and it was still a very positive experience for all : *"J'aurais aimé que ce soient les mêmes personnes, parce que c'était de belles personnes, mais que tout le monde parle français, ou que moi je parle plus anglais…" (Olivia, 33:00).* The experience remained a positive one, which offered her the skills to move forward in life. However, Olivia has felt that it would have been more beneficial without the language barrier among English and French speakers.

In contrast, Dan did not feel that it had negatively impacted his experience. He had pointed out that, although there were two groups within the activities (English and French),with time common ground was found over the expedition. There were some activities that didn't need language, which offered the whole group a chance to bond, such as playing "Hacky Sack."

> *"If we look at the kids, the participants… of course there were the two groups. Right off the top! But only because language was a barrier. And so you're like fourteen to eighteen on this expedition… and so at the beginning on the social side of it. Yes, it can be difficult. But as time passes… I spoke broken French, they spoke broken English… but in those groups, their common ground was found, and language didn't matter so much… Of course there were things in the expedition where you needed to be listening to the guides and whatever, but it's, you know, it's read to you in French and in English… To which they did a fantastic job, in my opinion, in always making sure that both the French and the English speakers had all the information" (Dan, 37:00).*

As an English-speaking individual, Dan did not feel like it was a hindrance in obtaining the most out of the support given to him. The Tip of the Toes Foundation does make important efforts in making the entire experience enjoyable despite potential language barriers, given that they serve all of Canada.

The participant also mentioned that in many contexts, such as sharing a tent during expeditions with other survivors that are francophone, sometimes language just was not an issue.

"You didn't need language to understand that the tent needed to go up. You just needed to put the tent up. So that sort of team-building exercise you know 'I can do this, I can go back into society, and I'm strong like I used to be'... those important parts of it are not lost just because you don't speak the same language" (Dan, 5:30)

Dan was able to experience personal development and community regardless of language barriers. He found common ground with his peers in their cancer experiences, age, and in the context of the expedition.

Other participants did notice a rift among the two groups that each spoke only one of Canada's official languages. David and Audrey both said that the groups were evenly divided during their respective nature expeditions, with David attributing his newly developed language skills to spending time with more English speakers with The Tip of the Toe's Foundation.

But the groups were overwhelmingly French during Leucan activities. David stated that there were mostly Quebecois participants, which, according to him, is normal because the foundation is based in Quebec and caters to Quebecois patients and survivors. He did point out that there was some diversity in the group, though not many visible minorities.

For Audrey and other participants, the Tip of the Toes Foundation was more evenly divided among English- and French-speaking participants. Even though the divide is more noticeable during these expeditions, likely because they are often significantly smaller groups, there is still noticeable camaraderie.

When Gabriel spoke of a bullying incident, he initially felt left out in the oncology camps due to it being overwhelmingly French Canadian. This led Gabriel to be avoidant of the summer camps because of other French participants. Instead, Gabriel attended the shorter weekend

oncology camps. English speakers were always a minority in these groups, and they sometimes formed their own cliques. He did express that, in the shorter oncology camps (winter and fall ones), there was some more linguistic diversity. Though everyone spoke French with one another, apart from the handful of anglophone participants, some also spoke their own language (Russian, Spanish, etc.) and there were moments where other survivors and entourage would share what languages they know to bond.

Although Gabriel's situation was quickly resolved with the foundation, there was a moment where the feeling of community was not easily obtained for him. It appears that, in this situation, the community is not only based on proximity to the diagnosis and the age group, but language and ethnic background as well. When listening to the participants speak on the negative experience they had at camp due to their discomfort speaking French, it becomes apparent just how much French-speaking campers take precedence over other spoken languages. That is not to say that the opinions of the two campers that had caused Gabriel discomfort reflected the foundation's views. Quite the opposite, this foundation, and others involved in this study, have expressed strong wishes in making their services more attainable to a larger diversity of survivors and families.

Lessons Learned & Improving Access:

Overwhelmingly, all the participants in this study had positive remarks on the help that they did receive. If any changes were needed, participants like Dan pointed out that the services had improved over the years, offering services that were even more beneficial as time went on. Two participants did mention that some improvements should be made following Covid-19 and the changes it created for the Leucan summer camps. There were no specific recommendations

by the participants, just a hope to return to regular camp activities prior to the pandemic, which has affected the oncology camps deeply.

Critiques that were noted were mainly due to availability. Olivia stresses that finding these programs needs to be much easier. A lot of support isn't presented directly at the core of treatment. She stresses that hospitals and oncologists should have more information readily available to patients and survivors. Psychosocial help is even less easy to find. She stated that this type of support is often overlooked given that it is not a directly biological need. However she points out that a cancer diagnosis not only disrupts a person's body, but also their personal lives and well-being. She points out that having to look for things that one is not aware of is a big barrier. It should be brought to light earlier on during treatment. She came across a lot of her support after chemo ended. This participant also mentioned that her professional background was helpful in finding the programs that she would have needed, given that she works closely with the medical and social fields. Olivia is aware that a typical person might not have these tools at their disposal, guiding them in their search for support.

"C'est par la suite que j'ai eu cette information la… pendant la chimio je ne pouvais même pas ouvrir mon cellulaire. Je n'avais pas les capacités attentionnelles pour ça. C'est après tout ça que j'ai vu qu'il y avait tout un monde [de soutien]" (Olivia, 51:30).

It is at this point that it becomes apparent that a lot of psychosocial support is dependent on the survivor being capable of finding out about and using it. Here Olivia stated she could not be receptive to any support that was presented to her. She was too tired from treatment to do so. Other participants said that there was a need for oncologists' approval before participating in certain activities like expeditions and oncology camps. The same oncologists would inform their patients of the opportunity. It is possible that she was not offered the chance at these programs

because of her health. But this situation would also suggest a potential gap in psychosocial support.

In short, the participants in this study are overwhelmingly happy with the support they have been offered. However, in some cases, they know it is not evenly accessible, and that there is a chance that a patient or survivor may not even be aware of the programs available to them.

Local Foundations' Accessibility Challenges and Goals (Leucan, FQC, Tip of the Toes):

Leucan

Leucan is attempting to widen the scope of their reach, not only in terms of language but also in terms of culture. The representative does state that a lot of the families that are being supported by Leucan are from metropolitan areas, with Montreal having more diversity than the other cities. What the representative does point out is that when they look at the families Leucan supports as a whole, they see the cultural diversity in that group but notice that some families of immigrant descent are not as present in the activities but do benefit from the other support that does not involve other Leucan families.

> *"We have patients, definitely from other cultures [...] I would say that, in terms of diversity, the francophone population is the most comfortable in those [in person] activities. The anglophones I would say are a lot more present than before." (48:30).*

This coincides with what the survivors speak of in their own interviews. There are more francophone participants in the activities offered by Leucan, especially during the oncology camps.

However, the Leucan representative stated that when the activities are offered already on location, there seems to be more willingness to participate in a group activity.

> *"What's interesting is that during the activities that take place in the hospital, that issue isn't there. If I am doing an activity in the playroom, it doesn't matter the culture, they will come!" (49:30)*

The representative questioned what the source of this participation discrepancy may be. They attribute it to potentially being linked to their culture, and possibly a question of what is comfortable for the family. For example when they are already in the hospital and out of their homes and comfort zones, it may be less daunting to take the next step and participate in activities. In any case it appears that Leucan can cater their support to a culturally and economically diverse population of Quebec families with a child that has been diagnosed with cancer. Their current challenge is bringing those families into their oncology camps and day activities that involve the social aspect of their support as well.

> *"Our association is very, very francophone [...] and because it is very francophone, for example, we might have a hard time figuring out how to reach out to, let's say, a [family who has immigrated from Southeast Asia and speaks neither French nor English as a first language]" (51:40).*

The representative goes on to explain how, in some cases, the cultural or religious foundation of an association can make it easier for families of those cultures and faiths to feel comfortable enough sending their children to their activities, seeing as they are more confident that their beliefs will be accommodated more than in a secular foundation.

In essence, they state that, to be more inclusive for their activities to a culturally diverse population of Leucan families, diversity ought to be reflected in the planning and implementation of the activities themselves. This could be accomplished by bringing in more diverse volunteers or having people advise the current employees on various cultural practices that could be integrated for those families. Language seems to be less of a preoccupation, but rather it is more important to make the in-person activities as welcoming as the personal support they already offer to many families.

Fondation Québécoise du Cancer (FQC)

At this point in time, the FQC is devoted to offering more accessible temporary housing near hospitals in urban areas. They currently have six cities where they can offer rooms for patients and a guest for a much more accessible price than any other method of temporary housing.

> *"C'est des logements a très très peu de frais, donc 30$ la nuitée pour les gens qui ont le cancer, et ça inclus leurs trois repas, donc des coupons pour leur repas à l'hôpital. Donc ça permet à ces gens-là d'éviter de payer un 100 ou 200$ pour un hôtel. Et on a une navette qui va jusqu'au CHUM qui les ramène après leur traitement. Et c'est vrai pour toutes nos hôtelleries. Même qu'il y ait certaines hôtelleries, notamment à Sherbrooke, qui sont même connectés à l'hôpital"*

It is also in these locations that they offer other support in the form of activities, such as art therapy, support groups, kinesiologist consultations, and other short form activities meant to support survivors. For the FQC, accessibility is more focused on geographical access, bringing services to a more rural population. The FQC is in the process of opening more locations in rural

areas, more specifically, a new location is going to be available soon in Rouyn-Noranda, at the request of hospitals, as this is an area that serves rural sectors that can often be harder to access for many patients that live far from their treating hospital, like Olivia.

This foundation reaches out to patients through the hospitals and their medical team and depends on them to relay the information to those that are being actively treated for their cancer. They decided to focus on providing care in rural areas that are often under-served, which, in turn, will improve accessibility to their care in a more geographical sense.

Another way the FQC is working on accessibility is through the sharing of information to minority groups. For example they are currently partnering with "Audace au Feminin" on a campaign urging visible minority Quebecois women to take part in government programs for breast cancer detection and prevention. They also have literature that is focused on medical minority patients, or what they call "orphaned cancers." This offers insight and information on those less known cancers that lack the visibility other better-known illnesses have.

In other words, the FQC does have some barriers to access that they do recognize and are actively working on improving. However, those barriers do not appear to be the same ones this project is focussing on. Nonetheless, the foundation does take into consideration the variation in the clientele and cultural and ethnic backgrounds. Their primary focus is bringing their support to rural areas by bridging the gap in access that is often created by geographical location and, in many cases, by economic precarity following a cancer diagnosis. The FQC also has some support catering to the younger age group of AYA survivors, again through partnerships with other foundations that already cater to the age group. Overall, most of their clientele are adults over the age of 50 years.

Tip of the Toes Foundation

For this foundation, the nature of the activities often requires the participants to be physically capable and to be fully present for the expedition. Their selection criteria are still quite large in that respect. Their expeditions can accommodate survivors that have had a limb amputation or who still experience fatigue and weakness.

The foundation does ask that participants' blood count would be high enough that their immune system is showing good function for such an activity. They always consult with the participants and their medical advisors to see whether it might still be possible for them to participate. Therefore, in terms of health status, there are not many barriers that are present to those that are in remission or in active treatment and that would like to participate in an expedition. The foundation mainly asks the person applying to participate to be honest about their capabilities, and the foundation can assess the situation further, if necessary, with their own advising medical committee as well.

A method to improve this barrier to access that the foundation uses is continuously working on their criteria to fit the potential participants and the expedition offered:

> " *A chaque expédition on met à jour la liste de ces critères et c'est envoyé dans les hôpitaux. Donc ils ont ça en tête… 'Mon patient en est-t-il capable? Est-t-il vraiment capable de marcher tant de kilomètres? Ou de soutenir un niveau d'activité physique plus grand que son niveau actuel pendant douze jours?' tout ça est connu par les équipes médicales" (Tip of the Toes Representative, 40:30)*

Essentially, in terms of medical diversity, the foundation seems to have it quite well figured out and continue to work on it to keep up with the fluctuating realities of young cancer survivors that are newly in remission.

Linguistic and cultural diversity are touched upon in a different way. It is something the foundation takes into consideration. However this competes with other priorities, for example, gender equality and affirmation:

> *"Ça va de soi que le cancer ça touche tout le monde. Donc dans les hôpitaux il n'y a pas de discrimination par rapport à ça. [...] C'est quelque chose qu'on garde en tête quand même et c'est toujours le fun d'avoir une plus grande diversité. Je te dirais que c'est plutôt un enjeu qui n'est pas culturel mais au niveau du genre pour les groupes de 30-39 ans. Parce que les seules personnes qui appliquent c'est des femmes, ou presque. C'est vraiment plus rare qu'on as des hommes" (46:00).*

For this foundation, gender is a bigger hurdle for them to overcome. As one of our own participants mentioned, the groups often represent a higher percentage of women survivors.

The representative goes on to explain that they have also been looking at deeper gender issues and wanting to open the discourse to more gender inclusive terms. They have worked on the forms and are providing more gender-affirming language:

> *"A part la dernière expédition, dans toutes les expéditions des deux dernières années il y avait soit une personne trans ou non-binaire qui se sont inscrites. Donc c'est vraiment un enjeu [important] pour nous" (48:00).*

The foundation has spent the better part of the last couple of years working on accessibility for survivors who are gender non-conforming. They have done so by doing research on their end but also by involving those who would be most affected in the discussion.

Essentially, the accessibility issues that interest them now have more to do with participants that are already starting to be more present in the expeditions. However, they may still encompass the issues of interest in this project:

> *"on a poussé la question jusqu'au fond je te dirais, et puis là on est dans la mise en place de ces nouvelles mesures là. Et d'ouvrir dans les discussions la question largement de l'identité. [...] L'identité du genre c'est une identité, mais il y en a plein d'autres. Pour certains l'identité du genre c'est plus ou moins important, mais la religion est très importante pour eux. Mais aussi pour que tout le monde puisse amener une partie importante de leur identité au groupe" (40:50).*

Gender identity is the starting point of the improvements in access that the foundation wants to implement. In other words, the Tip of the Toes Foundation's goal in terms of improving accessibility is rooted in open-mindedness and allowing all identities to be accepted and valued in the group and the nature expedition experience, whether it is about one's gender identity or religion, cultural identity, and/or linguistic difference.

Financial and geographic challenges are less of a priority currently, as the foundation covers all expenses for the participants despite the complicated economic situation and being a non-profit organization functioning on donations. The representative stresses that, in their years working at the foundation, the decision to take care of all expenses for each participant has never been questioned or in a precarious spot. The main barrier that they can enumerate is medical

status. At this point in time, the foundation recognizes that those who are in palliative care would benefit from these expeditions just as much as a patient in remission. However they do not currently have the proper amount of knowledge, or resources to provide this service. Therefore they cannot take on palliative care patients on a regular basis.

Discussion:

Overview of the Impact:

Short Form and Long Form Programs

This chapter took a closer look at programs and services offered by local foundations and associations that cater to young cancer survivors in Canada. One of the more pressing questions this chapter is meant to answer is how impactful community-based programs are catering to Canadian AYA cancer survivors, and whether language has any impact on accessibility to the programs. After speaking to six survivors who have all participated in programs, there seems to be a consensus that programs are overall deeply impactful in a positive way. It seems that the types of programs can often be categorized as either short form or long form programs, and each has their own benefits to survivors.

In both the literature and the discussions, improved independence is often a result of their experiences at camps and expeditions. Participants also report having improved confidence in their capabilities, which contribute to their wellbeing following the end of treatment by demonstrating to themselves their capabilities when leaving their newly restricted comfort zones.

In fact, most of the participants that report improved confidence following support programs are those who have attended activities along with other survivors of a similar age, such as camps at Leucan and expeditions with the Tip of the Toes foundation. It is also in these

activities that they find their capabilities, both physical and emotional, to be much more advanced than anticipated.

Programs that a survivor can typically benefit from without leaving their comfort zones and changing their routines drastically would be considered short form programs, such as classes, massage therapy, kinesiology, and financial aid. Those who have accessed short form programs have reported having a positive experience as well, but not as strongly as those who have attended camps or expeditions. That is not to say that they did not feel satisfied with their experience. Short form programs appear to be more so a way of offering immediate support, allowing the survivor to continue their lives with fewer stressors than they would otherwise have if they were not able to have, for example, financial support, or the tools useful to lighten the weight of treatment and early remission. Although this thesis was initially more focused on long form support programs, participants also stressed the importance of short form programs, and these should be included in a focal point in future research. Data highlighted in this chapter suggest the need for a variety of programs to meet the needs of the AYA cancer population.

Creating a Community

A crucial part in what makes programs so successful is the formation of a community. Respondents reported feeling more at ease in activities that allowed them to be surrounded by other survivors and patients. It became even more impactful when they were all a similar age. Camps and expeditions are most often the scene of such interactions. Participants would describe feelings of comfort being around others that are more understanding of their situation. In a seemingly contradictory sense, being surrounded by other cancer survivors and having the opportunity to speak of it openly allowed them to forget their situation. They were no longer "the sick person" but just another person in the group. Being like everyone else brought a sense of

normalcy to the survivors and long form support programs appear to have a longer-lasting impact on our participants. Many speak of their experience fondly and with deep sentimentality. In some cases, they continue to maintain the relationships they formed years ago during their expeditions and camps.

Interestingly, having a cancer diagnosis is not the only way to be a part of the community. A participant who was never diagnosed themselves, but had a sibling who had been diagnosed, expressed feeling part of the community as well. They had been able to attend programs and activities catering to this group because they were siblings. It seems that being near someone who is diagnosed with a condition is enough for someone to feel included in the community, to share the same feelings about the foundation, and to be around people of the same age. There is more to consider if the aim is to make the community more accessible to survivors and entourage alike. This implication is discussed in more detail in the next section.

Social Comparison

The concept of social comparison is easily observable in the context of these programs, and it seems to be an important aspect in creating a positive result when building programs for this group of young survivors. When speaking to our participants, every single one had described an instance where they had done either upwards or downwards comparisons. As mentioned previously, Meltzer and Rourke state that positive comparison should inspire the person to feel better or improve their situations and that better things are possible, whereas negative comparison is a coping mechanism that allows the person to feel better about their situation by comparing it to someone that might be worse off. In any case, to avoid a negative result, the two subjects must be sufficiently similar (2005).

This project's participants have voiced multiple times that a key benefit of the long form programs is the value of being surrounded by other survivors. Being around others like them allows survivors to feel like they are not alone and learning to cope by listening to one another's stories. In fact, the concept of social comparison is also helpful in concretizing the need for a specifically tailored support by age group. At least two of the six participants had mentioned that they felt out of place in short form programs or during their chemotherapy sessions even though they were surrounded by other cancer patients and survivors, simply because they were not the same age. Despite having the illness in common, the age gap often resulted in a more negative feeling from our participants following those activities. This shows just how necessary it is to focus the needs of survivors in accordance with their age groups. As observed in the case of this group, finding common ground with the next survivors is much more contingent on age. For example, one survivor has stated that they understood the positive impact and value of the activity itself but couldn't look past the fact that all the other people present were much older than them, which further alienated them by emphasizing how uncommon a cancer diagnosis at a young age is.

It is evident that for these programs to be successful, there need to be grounds for social comparison. However age is not the only intersecting characteristic. Gender, language, and ethnicity all have a hand in fostering the proper environment for social comparison, which can improve the perceptions of the participant.

For example, a participant mentioned that being in a group of all women during her expedition with the Tip of the Toes foundation was extremely helpful in creating an empowering environment. This was likely due to recognizing oneself in a group of women with similar health complexities and at a similar age.

Interestingly, language spoken is not as impactful as initially anticipated. Each participant was fluent in one of the two official languages, and volunteers were usually on hand to help with translation.

However, one participant demonstrated unsuccessful social comparison when speaking of a bullying incident during their time at an oncology camp. This situation was not caused by language, but rather by the lack of cultural representation, which left them unable to relate to a peer in a comparable situation. Though they were spending time with others in a similar medical situation, and in their age group, the kind of comparison that can be made with cultural identity was lacking for this participant. That is not to say that the program was wholly unsuccessful for this participant. But improvements could be provided here, which are on the docket for the foundation.

Essentially, using the notion of social comparison is crucial in anticipating how certain programs might be received, and therefore is a crucial tool in catering to this specific subpopulation. It is imperative that multiple facets of one's identity are considered when constructing the space for successful social comparison.

Overview on Accessibility:

Barriers to Access and Participation

The second research question of this chapter questions the impact language abilities may have on access to these support programs. A person's comfort level venturing into long form activities is what can influence whether someone would want to participate, while language seems to be part of various intersecting characteristics that can influence the comfort level. One indicator could be the potential formation of cliques in accordance with the languages certain

survivors would be more comfortable with. Being in a linguistic minority grouping could deter certain survivors from participating. This was observable in some instances with our participants, where one expressed discomfort around French-speaking survivors who bullied him for his accent, which led to some reservations about continued participation in summer oncology camps. In this case, not only is language ability an issue in participation, but culture could have had an impact on their reticence in further participating in long form activities.

As it was briefly alluded to in the previous paragraph, cultural background can intersect with language when speaking on comfort levels in participating in long form activities. A Leucan representative had mentioned the notion of comfort levels when speaking on the cultural diversity of Leucan families. Most of the families present at long form activities, such as their oncology camps, were Francophone or bilingual English and French speakers, likely because the foundation itself is strongly French. However, there is more diversity in Leucan families that benefit from their short-term programs. The Leucan representative interviewed went on to explain that the low comfort level of certain families may be due to their not recognizing their beliefs and value systems when they look at the programs offered by a foundation that is Quebecois. This shows that Leucan is thinking not just about linguistic diversity, but also how that intersects with cultural identity and representation.

In fact, the immigrant participants I interviewed who had attended long form programs were comfortable speaking in both Canadian official languages. In one case, the participant had stopped attending activities, since there was newly raised discomfort due to a bullying incident on their language capabilities. Another immigrant participant also stated that participating in these programs had helped them improve their French and English because they were surrounded by other participants who were fluent. However, both participants considered themselves fluent

in French or English, enough so that they felt comfortable participating in the first place. It is valuable to note that both immigrant participants mentioned here have attended secondary and post-secondary education in the province of Quebec and have done so without linguistic accommodation. The reticence to return to activities was for one participant a result of an isolated bullying incident, but it may reflect the discomfort one may feel if their knowledge of the main language of use is limited. Since all the foundations mentioned in this study function primarily in French, as they are based in Quebec, it may be especially important to think about how immigrants whose first language is neither French nor English can be supported.

Essentially, while language may not appear to be a direct buffer in accessibility to long form programs, it is at the very least an important measure for a survivor's comfort level, which is less of a challenge for accessing short form programs. Having an adequate comfort level can also have an influence on the depth of impact an activity can have on a person. Participants who did not experience language barriers during their time at camp or in nature expeditions appear to have had a much more favourable and longer-lasting impact than those who have had some struggles with communications.

Participants who experienced some level of language barrier with other survivors, whether they spoke French, English, or a different language, still reported having a positive experience, but did not recount their memories in as much detail or with as much fondness as others. They do, however, still express that their confidence in their capabilities has improved, and in some moments, language had less importance than the similarities they had with their colleagues on expeditions. In addition, the language barriers are not equal on both sides of the coin. French-speaking participants that were surrounded by mostly English speakers had a bit of a harder time forming connections, but when the minority was an English-speaking participant,

they expressed that their connections were still very strong, and that language often was not even necessary to form a bond. In any case, the foundation's employees and volunteers present at the activities always had the information and conversations translated, and participants recognized and appreciated the efforts.

In terms of initial access to programs, though all the foundations work in French, they also have every important document and exchange translated in English, to accommodate English speakers in Quebec and other Canadians if they serve the nationwide population of AYA survivors, like the Tip of the Toes Foundation does. The data collected did not show that there were linguistic issues in accessing the programs themselves. The participants expressed that all the forms and communication were bilingual, simple, and readily available to those who were eligible and interested. However it is of note that all the participants spoke or understood at least one of Canada's official languages, and were able to fill in the form themselves, regardless of their language spoken at home. All cancer patients and survivors involved in this cohort were initially diagnosed as adolescents or young adults. They already had the reading and writing skills to fill out forms themselves, even if the activity in question was meant for families of pediatric oncology care, and the parents had less ease with the language used in official correspondence with foundations.

Communication

Once again, while language does not appear to be in the forefront of accessibility barriers, it is an important part of the barriers that have been exposed in this project. The next potential barrier in accessing care, in short or long form, is communication. Most, if not all, our participants depended on their medical team to relay information on healthcare and on psychosocial care following the end of treatment. One had mentioned feeling so poorly during

their treatment that they did not have the energy or the emotional bandwidth to even start searching for resources. It was later that a person on her medical team referred her to a foundation that would support her. Many other participants had only been able to be a part of oncology camps and activities because they were sent information from the foundations themselves or by their medical teams.

While language was not the sole accessibility issue raised by this cohort, it may be an issue with other survivors, which can render communication more difficult, as providers may struggle to relay the information. The study's cohort also appears to have a good relationship with their medical team, which likely creates smoother communication pathways, and brings up once again the notion of trust that was mentioned by the Leucan representative. Essentially, language may not be the only issue in accessibility, but poor communication would be at the core of accessibility issues in this case. The initial theory was that speaking a different language may make it difficult for survivors and patients to seek out care, since much of it is offered in French or English, which I initially thought could explain the lack of linguistic and cultural diversity in many programs. What emerged from my interviews, however, was a somewhat more complex picture. Language is what could make the formation of relationships, trust, and effective communication much more difficult, and, in turn, create barriers to accessing care. In short, survivors and patients speaking a different language is not the sole issue. Indeed, language intersects with a range of other issues that, together, can sometimes create discomfort. To address such discomfort, programs need to be attuned to the complexities that, for example, intersect language, age, gender, sex, religious faith, and other identity markers.

Accessibility Priorities and Goals of Foundations:

The observations made align with the goals and projects of the foundations at hand. All of them are preoccupied with rendering their services more widely accessible to a diverse population of young survivors. At the core, much of the improvements they aim to make revolve around the comfort and trust of their participants. Communication methods remain dependent on the medical team to share with potential participants. Dissolving language barriers is not the main mode in which they aim to improve their services. For example, Tip of the Toes Foundation directs their attention to social issues that are of importance to the age group they cater to. More recently, they have concentrated on gender issues that have arisen over the last few years with the participants of their expeditions. Their goals remain to be more open and accessible and allow for the participants to be seen and comfortable within the sign-up process and during the expedition.

Similarly, Leucan's goals in accessibility improvement also depend on the comfort and trust from their participants. However, their focus is more so on cultural identity and creating a space where more participants of differing backgrounds will be comfortable in long form activities, like summer camps. They are looking at how they could translate the trust and comfort many of their families feel during the short form activities, into long form activities as well.

Lastly the Quebec Cancer Association's priorities to access are rooted in the geographical location of the participants. They intend to bring their services to the survivors in all areas of Quebec by being present in medical institutions offering healthcare to survivors. This method allows them to reach more vulnerable survivors that may have difficulties making their way to their current locations, which are larger metropolitan areas. And so, the Quebec Cancer

Association focuses on bringing care and support to rural areas to increase the reach of their services.

Essentially, all the foundations have their own priorities and methods in improving access to their own services. However, the goal remains the same: to offer helpful, tailored, and positive services and experiences to AYA cancer survivors. It appears that language on its own is not what creates barriers to care. I argue that a deeper understanding of health demographics is crucial. It is important to understand that, although cancer does reside in biological processes of bodies and environments, there is still a social, cultural, and economic aspect that must not be overlooked. Illness does not necessarily impact indiscriminately and may be more difficult for those who are vulnerable. Understanding that vulnerability, and how it comes to be, is crucial in moving forward towards better and accessible care.

Final Remarks:

To sum up the chapter, after speaking to nine participants, it has become more apparent that the work foundations and associations do for AYA cancer survivors is crucial and has important, positive effects on their lives. The degree of impact can correlate to the feelings of trust and communication among participants, their healthcare providers, and the foundations themselves. Language use can impact the degree to which a survivor feels comfortable accessing care, or even the degree of trust and the quality of communication they have with the healthcare provider, which is crucial in disseminating the foundation's information.

It is important to note that there are limitations in this section of the study. Future studies should aim to speak to more participants that have a diverse cultural. In fact, it would be valuable to speak to more survivors or members of their entourage that did not attend long form activities

such as camps. This would allow for more data on reasons why certain survivors opt to not be a part of camps or expeditions, despite literature suggesting strong positive results for those who do participate. Speaking to cancer survivors and patients who have not been able to benefit from any type of program or support outside of the hospital would also be valuable in understanding the reasoning behind why some people struggle to receive this care. Reaching a larger, more diverse group of survivors requires time and resources that were unavailable in the scope of this master's thesis project. Future research ought to concentrate on the concepts of trust, communication, and social comparison to better understand how accessibility can be improved and studied more closely.

Chapter 5: Discussion – Positioning Canadian AYA Cancer Survivors as a Subpopulation and the Language Implications for Accessibility to Support

The primary argument of this thesis was twofold. Firstly it was argued that AYA cancer survivors are a group that is substantial enough to be observed as a separate subpopulation. Second, as a subpopulation, there are needs that ought to be understood more clearly to meet them through formal support programs offered by charities and foundations that cater to Canadian AYA cancer survivors. It was initially hypothesized that the language spoken by the survivor would have a strong and direct impact on accessibility to these programs and activities; however, it was revealed that it is more nuanced than initially anticipated.

AYA Cancer survivors: A Subpopulation:

Like other groups, AYA cancer survivors still have needs and wants that are unified, in this case, by the presence of a cancer diagnosis and the effect it can have on their wellbeing. Literature and results clearly state that cancer survivors differ from those who have never had a cancer diagnosis in their lives (See tables 1–6). The results in this study show that there is a clear-cut distinction among survivors and those who have never had cancer when observing data on social development criteria such as educational attainment, income, age, and gender. It is also established that AYA cancer survivors report much lower wellbeing and poorer mental health than the rest of the general population (See chapter 3, table 2, pp.56). The size and consistent growth of this group only strengthen the need for a better understanding of it as a subpopulation. Such a significant portion of the general population cannot be homogenous in their needs. The results demonstrate that there is a variation within the group that is dependent on social categorizations as well as diagnosis. Much of the literature briefly alludes to heterogeneity in subpopulation but continues to study it in relation to their diagnosis, such as the type of cancer a

survivor has been diagnosed with (Dumas et al., 2016, pp. 1064). Prior literature focused on the kind of diagnosis when looking at the degree of poor mental health status or other emotional comorbidities but did not look at the social positions of their study subjects. In some contexts the previous literature used simple social demographic variables such as gender (De et al., 2020, pp. 15), which offered a shallow perspective of the differences that can be observed with AYA Canadian cancer survivors.

The results in this study do demonstrate that access to care and mental health status are not lived equally by each AYA cancer survivor (See chapter 3, table 15, pp.70). In the same way that the variation can be observed statistically, it can also create variation in outcomes. Results show that social characteristics affect the survivors' wellbeing and access to healthcare. Characteristics such as income and educational attainment do have an impact on their wellbeing. This variation is clearly visible in the data where higher income and education are correlated to better mental health, despite the established notion that cancer survivors have poorer mental health when compared to the general population (See chapter 3, tables 7–13, pp.60-67).

The sample subpopulation of Canadian AYA cancer survivors was strong enough to provide enough data to see that social determinants can affect access to healthcare significantly, which demonstrates that there is great value in observing them as a subpopulation for future studies. Regardless of what the results in this study say specifically, it is evident that there is, in fact, more to consider in future research. Previous literature has not delved deeply enough into how cancer survivors stack up amongst their own when observing mental health status and general wellbeing. Continuously comparing this group to the rest of the population is a reductionist approach to the study of cancer survivorship, and ought to be looked at in a more complex and intersectional light. This project has been able to demonstrate that there is some

variance among the AYA cancer survivor population in Canada; enough to consider for future studies.

Accessibility to Formal Support in Canada & Parallels with Healthcare Access:

The secondary argument of this thesis is the possibility of parallels and similarities between the way social determinants can act on healthcare access and on access to formal care.

Participant accounts indicate that there is a reasonable parallel that can be made in the comparison between healthcare accessibility and access to community support programs. Once again, English-speaking Canadians have ease of access to healthcare, and French-Canadian populations represent a significant proportion of Canadian AYA cancer patients and survivors (Ngwakongnwi, 2012, pp. 711). This suggests that knowing one or both official languages is an advantage when navigating the healthcare system. Similarly, the proportion of English and/or French-speaking participants in activities and programs offered to them is overwhelming (see chap. pp. 112). Most, if not all, the survivors or participants spoke at least French or English, regardless of their ethnic and cultural origins. The few times there were mentions of a different language were usually in passing, as either an interesting anecdote during an oncology camp, or as something that was overheard in the hallways of the oncology department, with a social worker and translator present (See chapter 4, pp.111). This shows that, like in healthcare, access can be influenced by the comfort one may have with the official languages. This can affect the ease in navigating the healthcare system and the processes involved in using the programs. It also implies that there is a lack of trust present when communication modes are not clear for both parties. The notion that trust, based on communication with medical providers, is reflected in the literature as well as in the data presented in chapter 3 of this project.

Interestingly, in the data presented, knowledge of official language did not show any significant correlations with the likelihood of having a regular provider or consulting a medical professional within the last 12 months, which in the context of this study reflects accessibility to healthcare (See Chapter 3, table 15, pp.70). The significance was noticeable when looking at the language spoken at home. English-speaking survivors are those who show the most ease in accessing healthcare providers and consulting for their mental health.

These results echo the literature as well. In parallel, the participants that spoke English also appeared to have the most ease with the programs offered, as even the French foundations would have all their official communication translated to both languages (See chapter 4, pp.111-112). In addition, the participants who spoke French primarily and knew English as a second or even third language had positive reactions to their English-speaking peers. Participants often quoted an improvement in their own English skills that would be useful in their professional and personal futures (See chapter 4, pp.104).

French-speaking participants did not report any difficulties accessing the services that would be provided to them by foundations. If there were any issues pertaining to language, it was only reflected during overnight activities where part of the group only spoke English. As already mentioned, those who knew English as an additional language did not report any issues with the matter. However, those who spoke only French struggled to form strong bonds with their peers when surrounded by English-speaking survivors (See chapter 4, pp.113). In these cases, the hindrance was not caused by speaking only French, as they had no issues signing up for support programs. In fact, when observing accessibility to both care and support in Quebec, French Canadians are strongly represented both in the results and in the existing literature. Immigrants and visible minorities are not as evenly represented (Ngwakongnwi, 2012, pp. 711). The data

demonstrated that visible minorities make up a smaller proportion of survivors than of the general population. The representation is even slighter when accounting for recent immigrant status. As mentioned previously, this is not an indicator of biological conditions that would render French-speaking Canadians more prone to cancer than recent immigrants, but rather a reflection of societal and cultural understanding of healthcare and how to navigate it.

The interviewees demonstrated this as well. Two of the six participants were immigrants, though both had enough comfort and knowledge with the official languages to get involved with Leucan and the Tip of the Toes foundations. The language they would speak at home with their families was not represented in the rest of their cohorts (See chapter 4, pp.98-99). Brief mentions of exchanges with other participants in a language other than French or English were recounted anecdotally (See chapter 4, p.114), but in most cases the programs were overwhelmingly offered in French first, and English second. This is not to say that there should have been more translations in the activities that the participants spoke on. They had all expressed their experiences in a positive regard. Rather it shows the group that was spoken to, as well as the other survivors they were surrounded by, experienced a lack of representation among their peers when observing the impact of psychosocial care.

Leucan spoke on the matter when interviewed. In fact, they state that there is a wider representation of cultural background among the families they serve than what has been visible to this study. They state that the cultural background of a Leucan family could be an indicator of the way a family opts to participate (See Chapter 4, pp.117). The representative quoted the level of comfort one may have as a buffer towards accessing care that is already offered to them, similar to literature citing a lack of trust in medical providers as a cause for low representation in healthcare (Perreira et al., 2012, pp. 6). Families of a visible minority background, or a minority

cultural group, are less likely to express an interest in the summer and weekend oncology camps that Leucan offers, which our participants confirm when speaking on the survivors that surround them during these activities (See Chapter 4, pp.112).

Just as our participants have noticed, the Leucan representative does state that French-speaking survivors are much more present in the long form activities offered. However, when speaking on short form activities that are offered in the hospital or in proximity to families that are often less represented in long form activities, they tend to be much more present (See chapter 4, pp.117). It is important to note that the disparity here is not viewed as something that is lacking in the families' desires and abilities to access such activities, but rather that Leucan has a need to provide a more engaging and inclusive environment for those families, especially in a time where support is needed and most poignant. This is something that Leucan is working towards by looking for opportunities for better representation for those families within the foundation itself (See chapter 4, pp.118). Individuals such as volunteers and employees that reflect the families' values would be best suited to offer the accommodations that would bring more comfort and build the trust that they need to fully benefit from the long form activities.

In this instance, the parallel in accessibility is quite apparent. Just as literature quotes a lack of confidence in medical professionals, rendering care less effective, there appears to be a lack of comfort in some of the more immersive programs available to the survivors. More research is required, however, to substantiate this initial observation of parallel accessibility issues across hospital-based support and community-based support. This would be a first step in understanding what sorts of barriers exist in access to psychosocial care. In short, we understand how social determinants of health can impact accessibility to healthcare; the existing parallel can

shed light on how those same characteristics impact access to care outside of medical settings in a similar way.

The Role of Language in Accessibility and Impact of Care:

The final argument of this thesis was based on language knowledge having a direct effect on both the accessibility to care and the degree of positive impact from participation. The original theory was that those who have difficulty with the official languages of Canada would have difficulty accessing social support. Accessibility issues could stem from the fact that pamphlets or intake forms are not available in a person's language of choice. They could also be caused by a lack of knowledge of the support available to a person, caused by the information not being available to them in their language.

It is still unclear if this assumption can be affirmed. The results of this project have not proven nor disproven the matter, and so at this point it is not feasible to definitively state that language on its own is a clear barrier to social support programs. As noted previously, the language spoken at home is a characteristic that can facilitate access to healthcare, and I was able to establish some parallels in the way certain characteristics impact healthcare and support accessibility (See chapter 3, table 15, pp.70). This demonstrates the value in moving forward with future research that can reveal how language directly influences the availability of such resources. Despite being unable to answer definitively, the role of language, communication and social comparison have been useful in understanding how information is transmitted to survivors and how the positive impact of support is achieved.

Communication Over Language:

The results and literature implied multiple times that clear and trustworthy communication is vital, especially with medical providers (Kasherman et al. 2023, p. 2052).

Much of the out-of-hospital support still starts in the hospital; trusted medical providers often lead the survivors towards the programs offered to them (See chapter 4, pp.110). This is where language can have some effect on accessibility. Existing literature also reported that having difficulties speaking the same language as the medical provider creates a breach in trust and in effective communication (Wong et al., 2014, pp. 12). Participants in this project have all stated that their first contact with the foundations is through the hospital. Nurses, social workers and oncologists were often the ones relaying the opportunities to participate in immersive activities such as nature expeditions and oncology camps (See chapter 4, pp.110). In some cases the medical teams were also personally involved as volunteers. Even the foundations have stated that their initial contact is a team effort with the hospital employees present for the survivors' care (See chapter 4, pp.112). Without this line of communication, many participants would not even be aware of what is available to them or even know where to turn to for help. Trust and comfort in communication is not something that is reserved for the patients and providers who speak the same language; we also see trust and comfort in cases where there are language differences. Further research on communication styles in the medical field could shed some light on the matter.

In short, it is simple to state that language is what can affect accessibility in this context. However, given that there are a multitude of characteristics and phenomena that can intersect when speaking on one's social position in relation to accessibility, regardless of if we are speaking on healthcare access or program access, singling out language tells only a partial story.

When speaking of language, it concentrates on the ability of the survivor to speak a language that is already in use with a foundation, or a medical provider who would otherwise recommend participating. A focus more broadly on communication highlights pathways beyond the language of forms and services that foundations and medical providers can improve. That is not to say that there is not an established mode of communication already. Evidently, charities and foundations have already had a great positive impact on those they have been able to support. The goal is to understand how we could reach more survivors that could benefit from it.

Impact of Care: The Notion of Social Comparison:

Initially, language was thought to also somehow impact the level of benefits a survivor can gain from their experiences with foundations and charities. The idea being that speaking a different language from your peers would be the first obstacle in positive results from social support. Though this is not entirely untrue, it is not the catalyst to a certain result.

Results suggest that the benefit to those who take part in programs is variable and reflects the literature stating that there is a clear positive impact of these types of activities that cater to this subpopulation (Martiniuk, 2014, pp. 786). Canadian AYA cancer survivors who have been part of an activity or program offered by foundations and charitable organizations overwhelmingly report positive outcomes to their wellbeing following participation (See chapter 4, pp.107-108). Although the impact is positive, it affects them at varying degrees, depending on the opportunity for social comparison. Activities that allow for more in-depth comparison and the formation of a relationship offer a longer-lasting effect on the survivor. Participants suggest that short-term activities where it is unlikely to get to know the other survivors, or where a survivor benefits alone from the service, are less likely to have a long-lasting impact (See chapter 4, pp.107). There needs to be an opportunity to spend a significant amount of time with like-

minded survivors. People who have similar life experience and are in a similar age group and have a cultural background that is compatible with the kind of comparison that is conducive to a positive result. Having the ability to either see oneself in others or compare their situation to another is often reported to have been the most impactful in recovery, but also in the formation of skills and qualities that would improve wellbeing in a survivor.

Immersive overnight activities like nature expeditions and camps offer an environment where the creation of a sense of community is possible. It also lengthens impacts or positive results following activities. Programs like those offered by the Tip of the Toes Foundation and Leucan resonate with survivors for a much longer time in their lives following the end of treatments. The benefits are clearly and enthusiastically expressed by the participants of this project, who have been able to take part in such programs (See chapter 4, pp.108). Playing into communication and trust could open the program to those who are not typically represented in these spaces and allow more individuals to benefit from this kind of psychosocial support.

Short form programs do, however, aid survivors in coping or fulfilling an immediate need that long form programs cannot meet. As mentioned, they tend to attract a wider scope of diversity in survivors. This is likely because short activities are less invasive in the day-to-day lives of a potential participant and require less commitment and trust. The Leucan representative I interviewed had pointed out that many times when an activity was taking place in the hospital, the survivors who tended to avoid the overnight activities were more likely to participate. They stated that it was likely because it was readily available and there was no need to leave the location they had to be in already, the hospital. Participants in this project also stated that the short form programs were helpful but also lacked the engagement with others that was so often praised in the overnight activities (See chapter 4, pp.103). In essence, a balance of both short and

long form programs will improve their wellbeing and ease the transition to their new normal following diagnosis, assuming the individual survivor is comfortable being a part of the activities and the support communicated to them by their medical teams.

Chapter 6: Conclusion:

In conclusion, we see that charities and foundations do have a great positive impact on the well-being of AYA cancer survivors. Literature and participant accounts show how helpful it is in their wellbeing. The aim of this thesis was to see how accessibility to these services can be improved to reach more survivors that will benefit from this support, which should be readily available to AYA cancer survivors and can be considered a crucial part in cancer treatment, or post-treatment.

To answer the research questions three main arguments were explored in the scope of this study. First, Canadian AYA cancer survivors ought to be viewed as a subpopulation and thus should be considered as such in future research. Through quantitative analysis, this notion was found to be verifiable. Previous research fails to fully grasp the heterogenous nature of this growing group by comparing cancer survivors to the rest of the population who had not been diagnosed. It would be a disservice to the Canada AYA cancer survivor subpopulation to continue to do research as if they were a homogenous group with needs unified only by the fact that they have had a cancer diagnosis. The intersection of social characteristics with their cancer status is crucial.

The second argument speaks of similarities in social determinants affecting access to healthcare and to social support. There was also a special interest in how language could play a role. It was found that there are some similarities that mean that future research could treat the barriers to accessing social support in the same way they would treat the barriers in healthcare access. Essentially, the literature stated that a lack of trust and comfort, which is reported to be caused by difficulties understanding medical providers, results in difficulty accessing support offered by foundations and charities. Meanwhile, the participants in this study, who have all

successfully accessed activities and programs catering to them, reported that their medical teams were often the ones giving them the information about these resources. In effect, communication, whether influenced by linguistic ability, is what can directly impact access to care, and not language on its own, but efficient communication is certainly achieved much more easily when there is no language barrier. What is important to note here is that communication from survivors is seldom aimed directly at foundations and charities, and it is dependent on their providers relaying the information and opportunities to the survivors.

The third argument was focused on how language affects the effectiveness of AYA survivors' support. While it was not possible to make a clear statement on how language could impact the results and access to psychosocial care offered by charities and foundations, other facets have been reported that can be useful in facilitating diversity in the participants but also in the volunteers and employees of the foundations. Trust, communication, and the potential for social comparison appear to be imperative in the success of these support systems catering to AYA Canadian cancer survivors.

Implications:

This thesis's results offer an avenue for future research on AYA Canadian cancer survivors. It argues the importance of the results facing the gap in the literature, which largely treats survivors as a homogenous group when they are anything but. It demonstrates that previous literature, though extremely valuable, often does not delve into the intricacies of this subpopulation. They have not been as reflective as they could be. Though much more could be uncovered than was found in this study, it is a clear demonstration of what is possible in the future. Social characteristics of survivors, such as income, education, cultural background, and language skills, are important in having a better understanding of potential barriers to accessing

support. This thesis has demonstrated that when research considers the intersectionality of a survivor's background and characteristics, meaningful results are attainable. Moving forward, research ought to consider that there is more to the data, and only considering a cancer diagnosis cannot offer a deep analysis into AYA cancer survivors while knowing they are a diverse subpopulation.

Following this, recommendations can potentially have practical implications. Having a clear understanding of social determinants, even in the context of a subgroup, will offer providers insight on changes that can be made to reach a wider clientele of survivors.

However, there might be a need to look at other methods of sharing the information with AYA survivors within Quebec, especially in light of recent political developments concerning the discussion around Bill 2 by Coalition Avenir Quebec (CAQ). This bill was introduced in October 2025; however, following strong opposition from physicians, the government recently announced that it would not enter into force as planned (Levesque & Cousineau, 2025). It was meant to modify the way doctors are compensated in the province: "Bill 2 imposes a new contract on Quebec physicians, who have not had a collective agreement since March 2023. Under this new law, 10% of physicians' salaries will be tied to performance targets set by the province" (Canadian Medical Association, 2025). The Quebec government states that this act was meant to give more responsibility to the providers in respect to access improvements to medical services (Bill 2, 2025). However, the presentation of this potential bill has been received with backlash from the physicians it involves. Many practitioners state that their capabilities are already stretched thin, and that implementing this bill will "risk exacerbating the sense of discouragement and disengagement in the profession" (Canadian Medical Association, 2025).

Since it's been presented, there have been protests from medical associations and doctors, which led to a strike that has caused many medical students in Quebec to lose training opportunities. This strike could potentially keep this cohort from graduating to begin their residency in the summer of 2026, and fewer practitioners will enter the Quebec medical system, while many current practitioners are looking for other opportunities outside the province of Quebec or considering an early retirement in the event that Bill 2 comes into force (Jaffer & Vo, 2025).

This thesis shows that communication among providers and patients is the main method of relaying information on programs and services offered by foundations. The impact of this bill could hinder this process. If providers are pressed for time to reach the quota imposed on them by the province, they might not have the time to build a trusting relationship for the kind of communication that is key in providing information on program services for AYA cancer survivors. In addition, the departure of doctors and medical professionals to other provinces, where performance pressure is not the norm, can also be a factor in diminished accessibility to care both in terms of medical care and psychosocial care.

Critics of this bill point out that it does the opposite of the goal that the CAQ had claimed would happen, if it does ever come to fruition. We can see that there are already negative implications happening with the potential implementation of Bill 2. The structural issues in Quebec's medical system ought to be addressed in order to improve accessibility. If patients have easier access to medical providers who have the time to understand the patients' needs, then accessing programs and services will not be hindered. Until providers are able to do so, it could be necessary to look at other ways of providing the information to AYA cancer survivors. Perhaps foundations and charities could appoint someone to this task and have a presence in

treatment centres to foster a relationship of trust and communication that medical providers may not be able to continue to do.

Research Limitations:

Like any other thesis, there are limitations in this study which are primarily in terms of resources. I was able to benefit from data that was collected by Statistics Canada for their Canadian Community Health Survey (CCHS). It was incredibly useful in the scope of this master's thesis. However, ideally, there would have been enough time and resources to create my own questionnaire that would be shared with respondents that were a closer fit for this project. Pooling multiple years of the CCHS was necessary to create a dataset that was substantial enough for this project. Despite these methods, certain manipulations were not possible to publish for confidentiality reasons.

Additionally, the time constraints that come with a master's thesis have also created limitations in this project. There was an issue of balancing the ambition of research and feasibility. Ideally, there would have been a larger sample size of participants for the qualitative component as well. Given the monetary and time limits that I had to work with, fewer survivors than originally anticipated were available for this project. In addition, it would have been beneficial to have more charities and foundations willing to participate in this project.

Ambition and feasibility were constrained by a lack of resources in other ways as well. Doing this project provided new avenues of research that could have been explored. While the main argument was focused on demonstrating that AYA cancer survivors ought to be studied as a subpopulation, it also presented a limitation of its own. I do still believe that future research needs to observe this occurrence. However, there is an aspect to it that I was unable to explore;

One of the participants of this study was the sibling of an individual who had passed from their cancer diagnosis. In the context of this study, they were able to provide insight to many of the same questions I had for the other participants who themselves were survivors. This is an individual who was very closely related to the cancer experience and had benefited from the psychosocial support programs that I strongly recommend. They were able to provide insight on the positive impact of the support and on the negative social and emotional issues following a cancer diagnosis. However, if this individual were to be a part of the surveys that were used for this study, they would not have been considered in the data, since they had not been diagnosed themselves. In the event of statistical manipulations meant to compare those who have never been diagnosed to those who have, this person could then potentially skew the data, even when there is the margin of error in place. Essentially, there is the possibility of a debate whether those who have never been diagnosed themselves, but have lived the cancer experience in any way, ought to be set aside in the context of research. Future research should delve into literature on the family members of cancer patients and survivors. In the hopes of finding the next appropriate steps for this debate.

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