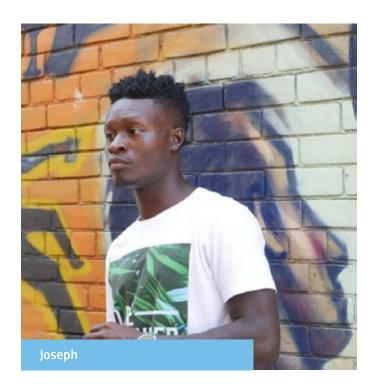


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Young adults go from thinking they have their whole lives ahead of them to losing that feeling completely after a cancer diagnosis. Now the goals that they've put on hold have to be rushed into fulfillment as they may not ever get that chance to reach their goals or dreams.

- Joseph, diagnosed with cancer at 20





The YAC Prime Study will help us bring the unique issues facing young adults with cancer into the light and put measures around the experiences of young adult survivors in Canada. This study will change how YACC provides support for this forgotten generation of cancer patients and it will empower us and our network to make positive change in the young adult cancer experience in Canada

- Geoff Eaton, founder and executive director of YACC

Two guiding principles at the core of Young Adult Cancer Canada's (YACC) mission are "cancer is different for young adults," and "it takes longer to recover from cancer than to be treated for it." Since 2000, we have been working with and for young adults diagnosed with cancer under the age of 40 and learning more about the impact cancer has on their lives every day. Through YACC-developed support initiatives like online programming and four-day faceto-face programs like Retreat Yourself and Survivor Conference, we have been connecting young adults to break the isolation they feel. This normalizes their experience and helps them process the trauma that is cancer. Unfortunately, there was little formal research to be found to support these statements.

The lack of awareness and evidence-based psychosocial information led us to partner with Dr. Sheila Garland of Memorial University and an incredible research team to develop the YAC Prime Study in 2017. The YAC Prime Study was a national cross-sectional survey of 622 young adults (YAs) diagnosed with cancer that aimed to understand their lived experiences.

This study, the largest of its kind to date, was also the first to examine the physical, social, financial, and emotional challenges faced by young adults diagnosed with cancer while comparing them to their non-cancer peers.

Cancer impacts every area of one's life, especially mentally, socially, financially, and physically.

The young adult population continues to be cancer's forgotten generation. Very little research and relevant resources exist in Canada. Things have improved in the last decade, but we are still neglecting this population and they deserve better.

Young adults will hopefully live decades past their diagnosis and our healthcare system cannot be the only resource they rely on. A better understanding of the impact cancer has on the lives of young adults can guide us in building better support services within the system and the community. This is where the YAC Prime Study comes in.



TEAM & PURPOSE

When I moved to Newfoundland five years ago, I made it a priority to meet with YACC. They started asking questions, and when I went back to the research to answer them, I realized there were no answers at all. These were not hard questions; they were questions like 'Is life really different for young adults with cancer compared to other people who haven't been diagnosed?' Nobody has really looked at it yet.

- Dr. Sheila Garland

WHY?

YACC and Dr. Sheila Garland, Professor in Psychology at Memorial University, identified a team of likeminded research partners to explore different aspects of this study. Incredible researchers, clinicians, and students from across the country and beyond were able to contribute to this study. With this supercharged team, we were able to pursue sub-studies and publish across notable and high-impact journals.

WHAT?

The research questions were:

What is the lived experience of cancer for YAs and how does this impact their psychological, physical, and interpersonal well-being?

Several important areas of functioning were assessed, such as sleep, body image, distress, fear of recurrence, coping strategies, social support, and post-traumatic growth.

How do levels of distress and social support in YAs with cancer compare with age- and sex-matched peers without cancer from the Canadian Community Health Survey (CCHS)?

This allowed us to better understand and communicate how cancer might be "different" for YAs. We hypothesized that YAs with cancer would report more stress, independent of their corresponding level of support.

We were also interested in understanding how feeling connected to the YA cancer community could impact psychological outcomes. We hypothesized that individuals feeling connected would have better outcomes.

WHERE?

Over a period of one year, 622 participants took part from across Canada. It was important to have diversity in geographical representation because we know treatment, feelings of isolation, and access to resources vary greatly between provinces and territories, cities, urban and rural environments, etc.



QUALITY OF LIFE

The mental health of survivors of AYA cancer is still significantly compromised compared to their non-cancer peers many years past treatment completion.

- Dr. Fiona Schulte

THE IMPACT

Participants rated quality of life subjectively in relation to their overall feelings of physical, psychological, and social elements of life. The data reported here is for YAC Prime participants who were more than two years out from the completion of treatment.

YAC Prime observed that YA survivors of cancer showed significantly worse physical and mental health ratings compared to their non-cancer peers. The factors associated with poorer quality of life were sleep, fear of cancer recurrence, body image distress, and need for social support.

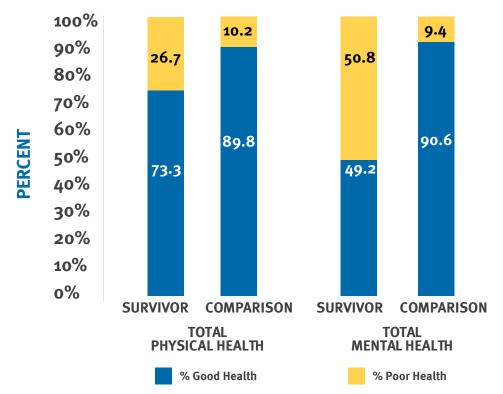
In our sample, 49.7 per cent of participants who were more than six years from the completion of cancer treatment reported poor mental health, and 31.8 per cent reported poor physical health.

WHAT CAN WE DO?

These findings emphasize the fact that it takes longer to recover from cancer than to be treated for it. It also highlights the urgent need for appropriate and specialized survivorship care and psychosocial support long after the end of treatment. Better interventions around sleep, fear of cancer recurrence, body image, and social support can have a real impact on the overall quality of life of young adults.

WHAT HAS YACC BEEN DOING?

Quality of life is a theme that is explored across many YACC programs! You'll especially see us translating this knowledge as featured topics in our psychoeducational programs like Primetown and Survivor Conference. Quality of life topics are also regularly explored in our YACCtivist blogs, our YACC Chats peer support program, and our webcast, We Get It!





It's fleen five years of chemo every six weeks and I'm fucking sick of it! I'm tired of feeling like shit, tired of not being able to get a job. I have to plan my life six weeks at a time and get really upset when my friends make plans the week I have chemo.

- Blair, diagnosed with cancer at 21

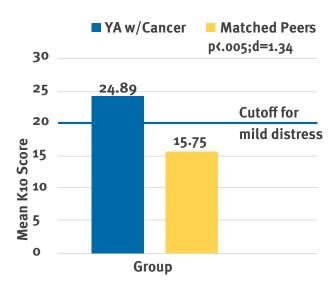
PSYCHOLOGICAL DISTRESS

Wondering how long you have to live leaves you constantly anxious and depressed because you feel powerless. Something has stepped into your life and basically taken over. Survivors still do their best to navigate around these issues but little support exists.

- Joseph, diagnosed with cancer at 20

THE IMPACT

Psychological distress describes the collective experience of depression, anxiety, and related symptoms. Our results showed that 46.7 per cent of participants experienced moderate to severe distress with 26.7 per cent reporting severe distress. When compared to their matched peers without cancer, we also saw a significant difference as illustrated below.



Body image dissatisfaction, fear of cancer recurrence, and poor social support were all associated with high levels of distress.

We also explored the relationships between distress and social support in rural and urban YAs and found those living in rural settings experience more distress than those living in urban settings.

WHAT CAN WE DO?

Understanding what factors are associated with distress can give us a variety of possible interventions that can all modify and improve distress levels in YAs. Many programs and resources for older adults already exist, adapting them for the young adult cancer population is important and needs investment and attention.

It could be important to take into consideration where the young adult lives, and pay special attention to their needs when living in a rural area where access to support services is often limited and can add to the struggle.

Finally, more fluid and constant collaborations between our health care system and community-based organizations would be quite beneficial in helping reduce the distress in the population. The mental health of YAs may continue to be impacted long after they have been discharged from their cancer centre or eligible for cancer centre psychosocial supports, so referrals for ongoing support may be essential.

WHAT HAS YACC BEEN DOING?

YACC offers many opportunities for young adults to find meaningful peer connection to support their mental health and relieve distress. YACC Chats are peer-facilitated online support groups where important themes are explored, normalized, and validated. YACC also runs online communities (like our private Facebook groups) where YAs can connect with peers for support 24/7. You'll find stories about mental health and resources to support distress across YACC's web programs.

FEAR OF RECURRENCE

With every new lump, bump or feeling of exhaustion, fear of cancer is the first thought that comes to mind. Once diagnosed with cancer there isn't a day that goes by without thinking about it.

- Nicole, diagnosed with cancer at 25

THE IMPACT

YAs with cancer show persistent distress and anxiety that their cancer will recur and uncertainty about future health. In our study, a whopping 59.2 per cent of participants reported experiencing clinically significant fear of cancer recurrence (FCR). The factors associated with a greater fear of cancer recurrence are:

- Time since diagnosis (the more recent the diagnosis, the greater the FCR).
- Having had a previous recurrence increased the FCR.
- Distress (moderate to severe) also meant more severe FCR.
- Body image dissatisfaction was related to higher FCR.

One in six participants reported spending a few or several hours a day preoccupied with thinking about the possibility of recurrence. Imagine spending time every day scared of a life-threatening illness coming back! For some, it is debilitating.

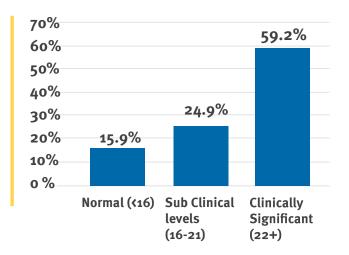
WHAT CAN WE DO?

Some very effective programs exist to mitigate FCR. Those programs have been built for and are mainly offered to older adults, but with some adjustments to make them relevant for YAs, it could be life-changing. We know YAs suffer from isolation, most times being the youngest in every room in the hospital. Having support services where they can be surrounded

by their peers and where FCR is addressed while taking their stage of life and issues into account can make a real difference. For example, FCR guidance for YA parents who are worried about the future for their children. Or FCR relief for those struggling with practical and existential questions of how to spend their time (Go back to school? Chase that promotion? Take a chance on a dating app?). There could be great opportunities in adapting interventions and resources to this unique stage of life. Programs integrating body image challenges and dissatisfaction, and considering YAs who have experienced a recurrence already, would be important to mitigate FCR.

WHAT HAS YACC BEEN DOING?

Fear of cancer recurrence has long been understood by YACC to be a major need of the community, but now we have evidence to back this up. FCR is heavily featured as a small group topic during our Retreat Yourself programs, and you can see resources, reflections, and opportunities for connection regarding FCR across our YACC Chats, YACCtivist blogs, We Get It episodes, and more!





I really wish someone would have told me how important sleep was for my cancer recovery and offered me support for it. I am five years post-treatment and I still struggle in many ways when I don't get a good night's sleep - including poor memory, low motivation and fatigue. It has impacted many areas of my life, my family, my friends, my work, and my health.

- Ryan, diagnosed with cancer at 33



THE IMPACT

Sleep and sleep disturbances can have a serious impact on the health of YAs and are overlooked in research and not addressed enough in psychosocial care. For example, lack of sleep can impact mood, physical health, relationships, and cognition.

The YAC Prime Study found 86 per cent of YAS diagnosed with cancer reported poor sleep quality, which is both significant and troubling.

Also, immediately post-cancer diagnosis, 52 per cent of YAs are likely to have difficulty falling or staying asleep. Sleep medication use was reported by 44.5 per cent of the sample with 20.6 per cent reporting using medications three or more times per week.

The study also found:

- Survivors with greater years of education reported better sleep quality than those with less.
- Survivors in school reported better sleep quality than those neither working nor in school.
- Survivors that were 2 to 5 years post treatment reported better sleep quality than those less than one year post-treatment.
- Clinically distressed survivors reported worse sleep quality than those who were not clinically distressed.
- Survivors in good physical and mental health reported better sleep quality than those in poor health.

WHAT CAN WE DO?

Again, some very effective interventions exist to help with sleep issues, but until YAs are informed of the impact sleep disturbances can have on their health and quality of life, and until programs and support are made available to them, things won't change.

WHAT HAS YACC BEEN DOING?

Our programs regularly incorporate workshops and sessions on sleep and ways to improve its quality of it. We also share research conducted on the effects of sleep on young adults affected by cancer across our social channels, and house content on the importance of sleep during cancer and beyond on our website.

BODY IMAGE DISTRESS

Body image is an issue people don't first think of when going through cancer. We either gain weight or lose weight because of the side effects of many drugs. We have to say goodbye to our hair, eyebrows, things that make us blend in with everyone else. And no matter what, you will have new battle scars you have to learn to love.

- Nicole, diagnosed with cancer at 25

THE IMPACT

Body image distress can be experienced by people of all ages regardless of a cancer diagnosis, but it is a quite prevalent challenge within the YA cancer experience. When diagnosed with cancer, the body goes through many changes from hair loss, weight fluctuations, scars and skin conditions. These changes affect how the body is perceived and how one feels in their skin. Yet, body image concerns are often overlooked and rarely discussed with YAs with cancer.

The YAC Prime Study showed that higher body image concerns were related to less time since diagnosis, lower post-traumatic growth and social support, greater distress, and a higher number of treatments received. Body image concerns were also higher for those currently on treatment.

WHAT CAN WE DO?

These findings can help us create and offer appropriate support to YAs diagnosed with cancer to minimize body image distress. YAs would benefit from discussions with their care teams on the possible impact cancer treatment can have on their bodies. The intervention should also plan for some long-term resources and tools to help as young adults live with, through, and beyond cancer.

WHAT HAS YACC BEEN DOING?

We regularly explore body image across our program offerings, but we have been working hard to increase the diversity of bodies and experiences expressed and shared in the YA space. The Insight team works with us to improve our access to the values, expertise, and perspectives of YAs with diverse experiences. We also regularly host a YACC Chat for 2SLGBTQIA+ YAs, creating further space to explore themes like body image in an inclusive and safe space.



When I'm looking in the mirror, I don't see me anymore (whoever that is). At least before cancer, I saw 'me.' Now all I see are my scars — not only the physical ones, but the emotional ones as well. I don't recognize the person looking back at me.

- Charlene, diagnosed with cancer at 37

FERTILITY

My husband and I are grateful for our son. He completes our family. And we are so grateful my oncologist recommended I preserve my fertility upfront before my high dose chemotherapy. Not all patients are given this advice, or are able to go through with the procedures.

-Alyssa, diagnosed with cancer at 32

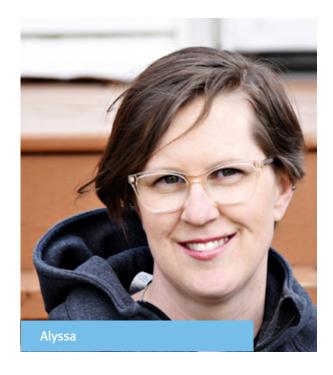
The YAC Prime Study took a slightly different approach when exploring fertility with its participants. We wanted to look into the prevalence of fertility preservation knowledge, discussions and engagement in young adults with cancer, and specifically explore the relationship of these variables with later post-traumatic growth (PTG).

THE IMPACT

We found that 81 per cent of participants reported an "awareness of risk" (how cancer treatment can affect fertility), 52 per cent discussed fertility preservation, and 13 per cent pursued fertility preservation.

PTG was higher for those with knowledge of fertility risk but did not differ between those who discussed fertility preservation versus those who did not, or made arrangements versus those who did not.

Those who did not go forward with fertility preservation because of their own choice or their doctor's recommendation not to delay treatment reported significantly higher PTG. This strongly suggests that when YAs are made aware of all potential risks, they feel better equipped to make the very best decision for themselves and also cope better with the outcomes.



WHAT CAN WE DO?

This study demonstrates the knowledge of risk, along with making the choice to prioritize treatment over fertility preservation, was related to higher PTG, suggesting informed decisions made early in treatment may support positive psychosocial outcomes. Providing young adults with clear and relevant information on the potential risk of cancer treatment on fertility is a difficult conversation to have, but an important one that can be empowering and offer long-term benefits. When we feel like we are supported and trusted to make the best choice for ourselves, the emotional healing and PTG can be positively impacted. Of course, each situation can be different and we should all use our best judgment on how these conversations take place.

WHAT HAS YACC BEEN DOING?

YACC's programs regularly share with YAs how they can meaningfully navigate their medical appointments and advocate for their needs, including fertility. Stories and spaces that touch upon fertility loss and preservations are featured throughout our programs and services. We have also been working with organizations like Queering Cancer to feature appropriate resources and reflections for 2SLGTBQIA+ YAs, as the topic of fertility is often framed heteronormatively.

FINANCES

YA survivors were more likely to have outstanding debts (e.g., credit card, line of credit balances), and less likely to hold assets (e.g., home ownership). YAs with cancer also face financial hardships in terms of additional expenses and missed work, with almost 60 per cent of YA survivors spending at least \$100/ month on cancer-related expenses, and 50 per cent missing at least one year of work. These results suggest that it is difficult for YA survivors to financially catch up to their noncancer peers.

-- Kaitlyn Nicole Mahon, YAC Prime research team member

THE IMPACT

We know that money can be a significant stress factor in one's life. YAs with cancer often find themselves in precarious situations. They are too young to have had a chance to save much money, to have made enough contributions to pension programs, or to have had a job for long enough to have financial security or health coverage. Many are still in school or looking for their first job, starting a new family, or moving into their own homes and fully embracing their independence. This makes them vulnerable, and cancer often means having to change or reorganize their plans. For example, many have to pause their education, take sick leave, or find themselves unable to return to work and having to live off income support programs through the government or private insurance provider. The study found 35.4 per cent of the sample quit work or school completely—yes, over a third of YAs diagnosed with cancer are in that situation!

It is also a misconception to think that healthcare has no costs for Canadian patients; from regular travel to

the hospital, parking, and non-covered medication, it can be very costly to go through cancer.

We have heard many stories of the financial strain cancer has had on this population. We felt like the financial health of YAs with cancer was negatively impacted compared to their non-cancer peers, but needed to explore further to see if it was actually the case. The YAC Prime Study was the first Canadian study to explore financial impact and recovery in a large sample of YAs with cancer. The results show a deep and lasting impact on YAs finances; they have extended periods of no or lower income, increased medical expenses, more bad debt, and fewer assets than non-cancer peers.

Here are some of the findings:

- 70 per cent missed at least six months
- 50 per cent missed school or work for 1-3+ years.
- 60 per cent spend at least \$100 a month on cancer-related expenses.



I have to take two weeks off every six weeks because of my treatment and have been on that chemo for five years; what kind of place would want to hire me?!

- Blair, diagnosed with cancer at 21



Income also had a strong relation to physical quality of life. We have found that those earning less than \$40.000 annually were more than eight times more likely to report poor physical quality of life than those earning more than \$80,000 annually. These findings should be interpreted with caution but knowing that the Canadian median annual income level in 2018 was \$61,000, it suggests that these individuals were struggling to maintain a basic standard of living. Even with some government support programs available in Canada, survivors of YA cancer are still clearly a vulnerable group. Addressing this issue is crucial as we think of recovery more holistically.

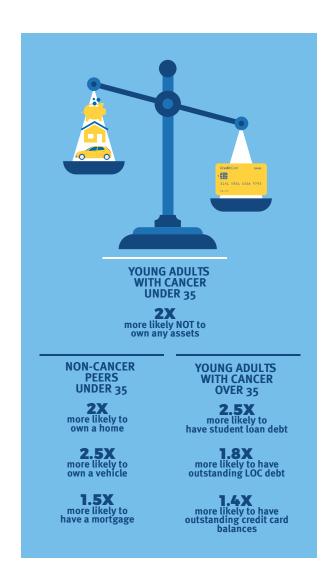
WHAT CAN WE DO?

Aside from normalizing the situation for many young adults who feel inadequate in managing their struggles, these findings can help us better understand the financial impact of cancer on young adults so we can think of different programs that can support their financial recovery. We hope these findings will influence government authorities, employers, HR departments, school administrations, and banks in their approach to dealing with YAs affected by cancer. Pausing student loan or debt payments would help thousands of YAs who carry more debt than their friends who didn't have cancer.

WHAT HAS YACC BEEN DOING?

YACC features financial support programs during our large psychoeducational events like Primetown and Survivor Conference. We also make sure that our program offerings remain cost accessible and often free to the YA community, and have supports available for YAs who may not be able to afford to travel to our in-person events. We also feature stories and connection opportunities on this topic, providing space for YAs to explore their own financial circumstances without shame, leading to a proactive, informed path forward.

When comparing our YAs with cancer with the noncancer peers, we also saw important differences as illustrated below.



THE POWER OF CONNECTION

THE IMPACT

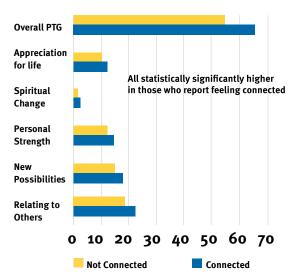
Isolation is one of the main issues faced by YAs with cancer. For over 20 years, we have been working to be the bridge out of isolation by creating and nurturing a community to support, inform, and inspire.

In 2006, Dr. Brad Zebrack found that young adults want the support of other young adults with cancer more than they want support from any other group. Parents and friends are still very important, of course, but they ultimately want and need to connect with their cancer peers. This is at the heart of YACC's mission and we strongly believe that being connected to others who "get it" can make a huge difference in the lives of young adults.

To support these statements with evidence-based data, we included questions within the YAC Prime Study to better understand the power of connection. We have found that those who feel connected to the young adult cancer community have:

- Lower levels of distress.
- Better overall mental health.
- Less body image distress.
- A positive effect on emotions, cognitions, and behaviours that are beneficial to health.

Post-Traumatic Growth and Connection



We have also found that a sense of belonging and connection to a community of peers can have a positive effect on emotions, cognitions, and behaviours that are beneficial to health. Those who do not feel connected to the YA community use less adaptive coping methods (i.e. positive reframing) and more maladaptive coping methods (i.e. behavioural disengagement, substance use, avoidance, etc.).

YAs with low levels of social support who feel connected to the YA cancer community are 3.5 times more likely to have greater post-traumatic growth than those who do not feel connected to the YA community, and 3.9 times more likely to have greater post-traumatic growth than those with high levels of social support. With that being said, even those who are well surrounded by non-cancer peers can benefit from being connected to the YA community.

WHAT CAN WE DO?

Refer, refer, refer to groups that serve the young adult cancer population! Groups and organizations like YACC do incredible work to help break the isolation and are in a position to support our health care system and its workers. Connection is a powerful tool accessible to all, let's make sure YAs know about it!

WHAT HAS YACC BEEN DOING?

YACC has prioritized safe and virtual options for connection since the beginning of the COVID-19 pandemic and will keep offering these programs post-pandemic. YAs have many opportunities to connect to one another through YACC. Localife offers in-person events in eight major Canadian cities for YAs to gather for events focused on fun, inclusion, and connection, like skating at a local pond or exploring a city aquarium. YAs seeking more casual connections can check out the Yakkity YACC program, where peers connect on Friday evenings to chat about their interests and experiences without a set agenda or theme. Our vibrant and active online community is also an easy way for our community members to connect, share, and feel supported.

CONCLUSION

The young adult cancer population continues to be a "forgotten generation" in oncology. We feel the YAC Prime Study has helped shed some light on areas that require attention and the data highlights the disruptive developmental impact of a cancer diagnosis during young adulthood. Key findings indicate the following:

- YA cancer survivors experience higher levels of distress compared with their peers, significant levels of fear of cancer recurrence, poor sleep quality, worse physical and mental health than the general population, and experience massive financial disruption.
- Conversations around body image and fertility are important.
- Social support and connection to others can buffer some of the negative effects.

These identified risk factors are modifiable and signify priority areas for additional supports, programming, intervention, and advocacy. It is encouraging to see that for most of the issues found through the YAC Prime Study, proper interventions on a variety of issues can have a ripple effect on other factors. For example, when working on reducing distress, we can have an impact on body image or FCR. Our healthcare system and psychosocial professionals can tackle one issue at a time and change things on a multitude of levels.

There are also extraordinary community resources that do work that can't be done by our existing healthcare system. Referral, proper collaborations and sharing of resources can make the lives of young adults better and the work of those caring for them easier •

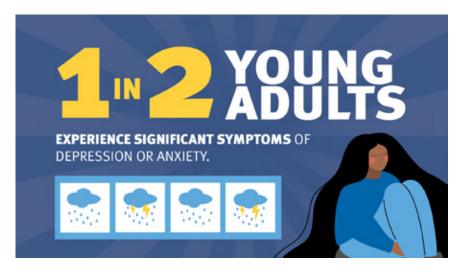


Thank you to our amazing team of researchers, to all the young adults who participated and to everyone who made this study possible. 'Til next time!



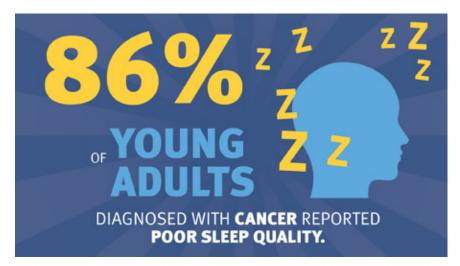






APPENDIX















ORIGINAL #YACPRIME TEAM



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Sheila Garland Memorial University

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THANK YOU

A special THANK YOU to Dr. Sheila Garland who came to YACC's HQ in 2015 with an open mind and an open heart. She had no other agenda than to work with us in creating something that would have an impact and help our incredible community of young adults.

Thank you to the extended research team, we could not have done this without your generosity of time and expertise. Your passion to improve the lives and experiences of young adults has been invaluable. Your flexibility and patience so very appreciated.

Huge thank you to the young adults who participated in this study and shared their stories. Your voices need to be heard and this was just the beginning.

A special thank you to CARE: Collaborative **Applied Research in Economics and NL** SUPPORT and the Memorial's Public **Engagement Accelerator Fund for** supporting the YAC Prime Study.

Together, we truly believe we have incited change and are excited for what is to come! Huge gratitude from YACC and all the present and future YACCers out there!



- Geoff, diagnosed with cancer at 22

The Young Adult Cancer Canada (YACC) team has worked closely with young adults affected by cancer for over two decades and has seen the devastating impact cancer can have on all areas of one's life.

The information found in this summary report supports longstanding truths we have witnessed first-hand such as how cancer is different for young adults, and recovery takes far longer than treatment. We compared the findings from data collected from young adults who had not been diagnosed with cancer and we now know that those diagnosed with cancer feel their quality of life is lower than their non-cancer peers with more negative outcomes in areas such as distress, sleep, body image, and coping; that their financial forecast is more greatly impacted; and more.

We feel the findings in this report are yet another set of reasons to rebalance cancer priorities in Canada—a rebalancing for young adults just starting their life but indeed for all Canadians. It is time to shift from satisfaction with increased survival rates to seeing and supporting people who are barely surviving. What kind of life are we living if we cannot love living it? The most courageous among us spend life turning pain into power to make change for individuals and communities. We hope you'll join us as we make this change for young adults living with, through and beyond cancer from coast to coast to coast.

The YAC Prime Study was only made possible by the contributions of the young adults who participated, the professionals and organizations who referred to it, the researchers who guided it and worked with the data and those who funded it. **On behalf of all the young adults we serve, thank you.**

These findings affirm YACC's next chapter of the young adult cancer story in Canada. YACC will embark on a longitudinal study of the young adult cancer population that will dig deeper, shake the tree of assumptions harder and continue to make change for cancer's forgotten generation.

Always...

Live life. Love life.

beoff Eats

Geoff Eaton

yacc

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