THE PSYCHOLOGICAL CONSEQUENCES OF CANCER IN CANADIAN YOUNG ADULTS: A NATIONAL EXPLORATION OF PSYCHOLOGICAL DISTRESS AND FEAR OF CANCER RECURRENCE

by © Breanna Ellen Lane

A thesis submitted to the School of Graduate Studies
in partial fulfilment of the requirements for the degree of

Doctor of Psychology
Memorial University of Newfoundland

May 2021
St. John’s, Newfoundland and Labrador

Abstract

This project is a cross-sectional exploration of the psychological challenges experienced by young adults (YAs), age 15 to 39, with cancer in Canada and includes two published studies. YAs with cancer across the country completed an extensive online survey, which collected demographic information, cancer history, and included psychometric measures of psychological distress, fear of cancer recurrence (FCR), body image, sleep, well-being, posttraumatic growth and social support. Responses from 508 participants diagnosed with cancer in young adulthood were collected to answer the research questions across the two studies, but the number of participants included in each analysis varies based on completion of outcome measures and matching characteristics.

Participant responses from 448 YAs were used to explore whether high psychological distress reported by YAs with cancer is driven by developmental stressors shared by YAs generally, or represents the intersection of cancer and development stressors. An equal number of participants who completed the same distress measure were randomly sampled from the national Canadian Community Health Survey (2012) to create a non-cancer comparison group matched on age, sex and education. YAs with cancer reported significantly greater levels of distress, were less likely to be living independently, and less likely to report annual incomes greater than $40,000. Individual factors associated with experiencing high levels of distress included not working, body image dissatisfaction, poor social support and high FCR. Higher levels of education were a protective factor and associated with decreased likelihood of experiencing high distress.

To better understand FCR in YAs with cancer, the responses of 461 participants were utilized to assess prevalence within this population. The prevalence of clinical levels of FCR for YAs with cancer in Canada was 59%, and an additional 25% reported problematic levels. Individuals with a previous recurrence, distress, and body image dissatisfaction were more likely to experience clinical FCR, while those diagnosed with cancer five or more years ago were less likely.

The pervasive nature of mental health challenges for YAs with cancer emphasizes how essential psychological support is for this population. Comprehensive, holistic and YA-specific programs are needed to address the developmental needs of YAs with cancer in Canada.

Acknowledgements

This thesis is the result of extensive practical, academic and emotional support, which is impossible to accurately recognize; however, I endeavour to do my best in my comments below. Firstly, I am incredibly appreciative of my supervisor Dr. Sheila Garland's invitation to join the Sleep Health and Wellness Lab. I remain amazed at all of the incredible opportunities I have had participate in the field of psycho-oncology, and I am truly grateful for your enthusiasm and passion for research. Thank you to Geoff Eaton and Karine Chalifour of YACC for being amazing research collaborators and allowing me to be a part of a project I am immensely proud of. A similar thank you goes out to the incredible YACC network for sharing their experiences to help us advocate for the different needs of young adults with cancer. Additionally, the two published studies would not have come together without the expertise of Drs. Ken Fowler, Sophie Lebel, Jacqueline Galica, Christine Maheu, and Sébastien Simard, and my committee Drs. Nicholas Harris and Martin Day.

It would not be possible to be sitting here today without the tireless support of my parents, Barb and Brian Lane. Thank you for being my cheerleaders and always thinking I am brighter, more capable and more resilient than I feel, and helping me believe "I am smart and intelligent too". To Ben, I am absolutely grateful for your love, patience and efforts to be the anchor I needed to help me survive the turbulent seas of grad school. I am endlessly thankful for my PsyD classmates and "family" who made this one of the most rewarding, transformative and fun chapters of life. Shannon, Chris, Alysha, Rachel and Brandon, thank you for getting me to this point, conceptualizing my challenges and accepting my sarcasm – I'm so grateful to have you all in my life. Lastly, Emily and

Lauren, my fellow members of the PsyD Sorority House, thanks for making every household activity an adventure and making St. John's feel like home.

Table of Contents

List of Tables

Chapter 2

Chapter 3

Chapter 1: Why Cancer is Different for Young Adults: Using Patient-Oriented Research to Address Current Knowledge Gaps

1.1 Overview

This thesis is a population investigation, including two different studies that explore the psychological consequences of cancer in young adulthood within a national sample of individuals diagnosed with cancer between ages 15-39 that reside in Canada. The first chapter will provide an overview of the literature that illustrates the theoretical motivation for these studies. This chapter begins with a brief explanation of the development and evolution of psycho-oncology, the added developmental challenges associated with a cancer diagnosis in young adulthood, the relationship between cancer and mental health, and how to apply patient-oriented research and knowledge translation to young adult (YA) cancer research. The first chapter concludes with a summary and the research objectives. Study 1 explores whether a cancer diagnosis contributes to greater psychological distress during young adulthood through comparison to matched peers. It also identifies factors associated with higher distress in young adults with cancer. Study 2 examines the prevalence of fear of cancer recurrence, a cancer-specific psychological outcome, and the factors associated with clinical presentations of fear of cancer recurrence for young adults. The final chapter will contextualize these findings within the existing literature and explore implications for clinical practice to better meet the needs of young adults with cancer. Directions for future research are also outlined that emphasize patient perspectives in the development of interventions and in exploring the relationships among the key psychosocial concerns reported by YAs with cancer in Canada.

1.2 The Development of Psycho-Oncology

In the 19th century, there was little knowledge surrounding cancer's cause, treatment, and pain management; consequently, a diagnosis associated with substantial social stigma and patients were rarely informed of the diagnosis (Holland & Rowland, 1989). Advancements in knowledge and treatment contributed to significant improvements in patient outcomes, which coincided with transitions in early psychiatric philosophy, and the integration of psychiatric services into hospital settings (Watson et al., 2014). The 1950s represented a significant shift in psycho-oncology development by establishing the first psychiatric and clinical research group within a cancer centre and the emergence of self-help and patient support groups (Holland & Rowland, 1989).

The growing role of psycho-oncology internationally in the 1990s prompted the development of treatment guidelines, measures to quantify patient's reported psychological symptoms and determine contributing factors, and specific language to describe the psychosocial impact of cancer (Holland, 2004; Watson et al., 2014). The term distress was selected to capture the experience of collective unpleasant or painful psychosocial responses that impair effective coping with cancer (Watson et al., 2014). Psychological distress can present as depression, anxiety, somatic symptoms, impaired relationships, and existential concerns (Howell & Olsen, 2011). Distress is now recognized as a the sixth vital sign alongside the other vital signs of respiration, temperature, heart rate, blood pressure, and pain (Bultz & Carlson, 2005). These developments occurred adjacent to advancements in behavioural research supporting modification of lifestyle factors to improve health outcomes and increased cancer prevention education (Breitbart & Alici, 2009).

The development of psychosocial oncology has had a drastic impact on both the quality and cost of medical care (Carlson & Bultz, 2003). In determining the specific impact of psychosocial symptoms on healthcare, research has illustrated increased fatigue and distress relates to increased medical spending (Carlson & Bultz, 2003). Lebel and colleagues explored the relationship between healthcare utilization and fear of cancer recurrence (FCR) in breast cancer survivors (n=231) (Lebel, Tomei, et al., 2013). Using the Fear of Cancer Recurrence Inventory and the Healthcare Utilization Questionnaire, they demonstrated that within six months, participants with high FCR, when controlling for demographic factors, had increased outpatient and emergency room visits, indicating higher healthcare costs.

Conversely, psychosocial interventions can reduce psychiatric symptom burden, improve mood disturbances, and reduce pain, healthcare utilization and medical costs (Carlson & Bultz, 2004). In Simpson and colleagues' six-week cognitive/behavioural group intervention designed to improve psychological functioning adjustment to cancer, the intervention resulted in a 23.5% reduction in medical billing and improvements in psychological symptoms and well-being (Simpson et al., 2001). Participants were not selected based on the severity of distress symptoms; therefore, this likely underestimates the economic benefits of a psychosocial intervention for participants who have more severe distress (Carlson & Bultz, 2003). A systematic cost-analysis of 12 studies examining individual and group-based psychosocial interventions concluded that psychosocial interventions are cost-effective within cancer healthcare (Dieng et al., 2016).

Variability in screening and psychosocial interventions limits the generalization of effectiveness studies, yet research using systematic screening methods for distress and subsequent psychological interventions has demonstrated positive outcomes for reducing significant distress (Shimizu, 2013). Additionally, an early meta-analysis of randomized controlled trials (n=62) examining the impacts of psychosocial interventions for adults with cancer, comparing patients receiving psychosocial services to individuals completing control tasks or not participating in interventions, revealed significant, small effect sizes across psychosocial domains (Meyer, 1995). Overall, patients engaging in interventions reported improved emotional adjustment outcomes, functional adjustment, disease-related symptoms, and global measures related to many categories, providing insights into the practical value of psychosocial interventions within this population.

The above research illustrates the clinical and economic value of psychosocial care. However, research has largely failed to capture the experience and impact of a cancer diagnosis in young adulthood, a particularly vulnerable developmental period.

1.3 The Impact of Cancer in Young Adulthood

YAs make up a distinct population within the broader cancer care community. YAs with cancer are defined as individuals diagnosed with cancer between ages 15 and 39 (Adolescent and Young Adult Oncology Progress Review Group, 2006; Aubin et al., 2011). Individuals belonging to this population share similar physiological and biological characteristics, including hormonal maturity, unique tumour development, delays in receiving a diagnosis as YAs are often assumed to be "healthy," leading to underrepresentation in clinical trials (Bleyer, 2005). A cancer diagnosis in young adulthood can disrupt typical development resulting in significant psychological, developmental, social changes. YAs with cancer report higher levels of unmet psychological support needs, deficient care-seeking patterns, and lower adherence to recommended treatment and follow-up care, which have been linked to worse disease outcomes (Galan et al., 2017). Due to the age and life stage at diagnosis, YAs face different psychosocial vulnerabilities related to their physical health and well-being (Park et al., 2014).

Identity and Relationship Development

Young adulthood is mired with psychosocial developmental tasks and includes an emphasis on transition, autonomy, and individual identity (Zirkel & Cantor, 1990). Developing autonomy within parental relationships is an essential part of identity and relational development in young adulthood (Fullinwider-Bush & Jacobvitz, 1993). Stable individual characteristics, including socioeconomic status, gender, and race/ethnicity, may be the basis for identity development; however, these factors are also influenced by physiological development/maturation, familial culture, and psychological functioning (Benson & Elder, 2011). Interpersonal relationships are often altered for YAs with cancer, including an increased reliance on others (Siegel et al., 1999). Changes often contribute to feeling socially isolated and managing others' emotional responses to the cancer diagnosis (D'Agostino & Edelstein, 2013). Research using collateral familial information to examine the social outcomes of YA brain tumour survivors (n=19) identified themes of poor social adjustment, withdrawal, poor social processing and communication (Wilford, 2017). The relationships of individuals with cancer and their partners are among the most negatively impacted life domains reported by YAs with cancer (Bellizzi et al., 2012). A systematic review examining the impact of cancer on romantic relationships for YA cancer survivors (n=21) identified distinct relationship challenges related to cancer diagnosis (Rabin, 2019). These concerns include how and when to disclose of cancer history and the content of this disclosure, regardless of individual demographic characteristics of sexuality, gender, race and ethnicity. This review also suggests that YAs with cancer are more likely to experience delays in developing relationships, getting married, having children, and experiencing more adverse emotional responses when these relationships end.

Family formation, the transition to parenthood, and subsequent changes in relationships are also fundamental developmental tasks of young adulthood (Committee on Improving the Health, 2015). Survivors who experience disruption in these areas are more likely to report impaired psychosocial functioning long into survivorship. A systematic review of the literature (n=47) examining the prevalence of fertility-related distress for survivors (Logan et al., 2019), reported increased rates of mental health symptoms, including depression, anxiety and trauma at diagnosis and during early treatment phases while accessing fertility preservation and compounding distress related to diagnosis. Further, female survivors without biological children before diagnosis may be particularly vulnerable to adverse mental health, and more significant overall distress. Canada and Schover examined the impact of cancer-infertility on long-term well-being for women diagnosed with cancer in young adulthood (Canada & Schover, 2012). Assessments of overall physical and mental health, psychological symptoms, the impact of cancer and reproductive concerns were completed with 240 women who had been diagnosed approximately 10 years prior. Distress reported by this sample was highest among women without children. Those who were unable to conceive were more distressed, had more intrusive thoughts, and used more avoidance coping with infertility. Cancer-related infertility in young adulthood is a lasting consequence of cancer, permanently altering patients' lives and contributing to long-term psychosocial impacts.

Patients may also experience distress and impairments in quality-of-life and mental health symptoms with worry about the impact of health on family functioning (Park et al., 2017; Park et al., 2016; Park et al., 2019). Qualitative research with young and middle-aged adults (Age: *M* = 44.2, *SD* = 9.0) with cancer (n=42), with children younger than 18 years old, reported prevalent concerns relating to the impact of their illness and death on families, cancer as a barrier to life experiences and typical responsibilities, and how the role of being a parent influenced treatment decision-making (Park et al., 2017). In a similar study, Park and colleagues examined parenting concerns, quality of life and distress in a sample of patients (n=63) diagnosed with stage IV cancer (Park et al., 2016). Researchers found that greater parenting concerns were significantly related to higher levels of depression and anxiety and reduced quality-of-life. The relationship between parenting concerns and mental health symptoms within this population suggests that disruption of developmental objectives (i.e., parenting) may influence the relationship between cancer diagnosis in young adulthood and impaired psychological functioning.

Education and Occupational Development and Financial Consequences

Beyond relationship-related developmental factors, young adulthood is also crucial for initiating careers and making decisions relating to life planning and establishing professional identities (Konstam, 2015). A cancer diagnosis can have significant negative financial consequences with increased medical expenses and disruptions to productivity during this time. Comparing financial indices between individuals diagnosed with cancer in young adulthood (n=575) and age, sex and education-matched peers (n=575), Mahon and colleagues demonstrated that survivors do not recover financially from the disruptive impact of cancer during this vulnerable period (Mahon et al., In Press 2020). Specifically, YAs were more likely to report debt and fewer assets than non-cancer peers with differences maintained in middle-aged participants. Using data from the Medical Expenditure Panel Surveys (2008-2011) in the US, Guy and colleagues compared the direct medical costs, employment disability, and missed work between 1,464 YAs with cancer and 86,865 participants without cancer (Guy et al., 2014). Compared to non-cancer peers, YAs with cancer reported $3,170 greater in medical expenses and $2,250 in productivity losses annually. Overall, YA cancer survivors were less likely to be employed and more likely to report limited financial resources. These findings are consistent with a meta-analysis created by de Boer and colleagues, which pooled the results of 36 international studies comparing employment rates between adults (age 18 to 60) with control participants (de Boer et al., 2009). The overall pooled relative risk of unemployment was 33.8% for adults with cancer, compared to 15.2% for healthy adult controls. Long-term financial consequences of cancer can compound the disparities experienced by YA cancer survivors, making it increasingly challenging to address this population's identity and relationship concerns.

Unemployment reflects difficulties and barriers associated with return-to-work for YAs with cancer. Parsons and colleagues used cross-sectional national data from the AYA HOPE study in the US to examine return-to-work within a sample of YAs (n=388) (Parsons et al., 2012). This study demonstrated that 72% of YA cancer survivors who engaged in full-time work or school before diagnosis returned to work, compared to a national average of roughly 80% for this population (Parsons et al., 2012). Being uninsured or quitting work after diagnosis was associated with a decreased likelihood of returning to work and may contribute to unemployment rates more broadly among YAs. Additionally, participants were more likely to believe that cancer negatively impacted their career or educational plans if they had received physically intensive treatment or had left their jobs or schooling.

YAs who return to work or schooling may still experience lasting impacts of their cancer treatment and report subjective cognitive impairments that impact occupational functioning (Parsons et al., 2012). In a study comparing YAs with cancer (n=23) to matched peers (n=14), survivors performed poorer on vigilance, processing, and attention-based tasks (Nugent et al., 2018). Small to medium effect sizes were also reported for worse perceived total cognitive functioning, including memory, executive function, language, orientation to place and time, and sensorimotor ability, suggesting survivors may experience further impairments if returning to work. Using semi-structured interviews Elsbernd and colleagues interviewed YAs (n=9) diagnosed with cancer while attending school to identify salient themes regarding transition back into their education (Elsbernd et al., 2018). Participants reported misunderstanding and lack of empathy from peers and physiological treatment symptoms as barriers experienced by YAs trying to return to school.

The impact of cancer extends beyond occupational engagement, contributing to changes and subsequent challenges related to satisfaction and career development. In an ethnographic study, Rasmussen and Elverdam used observational and interview data from 23 cancer-free survivors who had completed a week-long residential rehabilitation program addressing physical health and psychosocial well-being (Rasmussen & Elverdam, 2008). Interviews were conducted immediately after completion of the program and 18 months later. Three central themes were identified by participants across both time points, including the disruption of their work lives, re-entry into work, and life without work. Experiences shared by participants suggests that individuals who are not able to return to work may experience grief related to identity loss, and consequently need to determine new areas of their lives to derive satisfaction and achievement. In a similar qualitative study with 13 YA women working full-time when diagnosed with breast cancer, participants identified workplace challenges related to cancer (Raque-Bogdan et al., 2015). Challenges included the need to re-examine career paths, with increased importance regarding balance, engaging in more value congruent work, and changes in ambition. These factors may contribute to further delays in return-to-work due to exploring alternative options that contribute to motivation, reflect changes in values or impact satisfaction. Consequently, YAs with cancer who tolerate treatment and manage physical and psychological symptoms continue to be at risk of disruptions to psychosocial functioning. Barriers to reintegration into the workforce have considerable financial implications for YAs with cancer and can pose further difficulties with autonomy, family planning and asset acquirement, illustrating how occupational disruption can pose further challenges.

Existential distress

YAs with cancer may also experience existential anguish through confronting their mortality (Siegel et al., 1999). Odh and colleagues evaluated the existential challenges reported by YAs with cancer in Sweden using an analysis of six blogs written by YA patients (Odh et al., 2016). Participants' blogs identified four themes: (1) existential thoughts on death, including the disruptive impact of cancer on plans; (2)

uncertainty; (3) trying to engage in their pre-cancer lives; and (4) meaning-making. Qualitative research confronting existential concerns has meaningful consequences for YAs ability to cope with everyday stressors and work towards long-term goals (Benton et al., 2014). Utilizing patient perspectives to inform treatment and services (Ngwenya et al., 2017), and guide psychosocial interventions (Gagnon et al., 2015), are likely to be more effective at meeting needs to reduce existential distress for YAs. While qualitive studies are valuable, it is also important to note that the studies describing thematic issues for YAs with cancer often include very small sample sizes (Odh et al., 2016; Raque-Bogdan et al., 2015), which limits the application to the broader YA population. Larger population studies that explore and complement these themes would be beneficial in assisting with generalizability of the findings.

YAs coping with cancer experience the same grief and fear related to diagnosis, pain and discomfort, and distress as other survivors across the lifespan; however, these experiences are exacerbated by the different developmental demands associated with young adulthood. Disruptions to identity development, relationship formation, educational attainment, financial security and difficulties processing existential crises at best leave YAs fighting to achieve the same milestones as same-aged peers or, worse, have the trajectories of their lives permanently altered. To address gaps in current healthcare, YAs with cancer require tailored research and interventions to address their needs as a distinct population within cancer care.

1.4 Cancer and Mental Health in Young Adults

The bidirectional relationship between physical and mental health persists across the lifespan (Ohrnberger et al., 2017; Steinmo et al., 2014) and there has been growing academic advocacy for mental health research within oncology (Martinez, 2017; Niedzwiedz et al., 2019). The prevalence of adolescent and young adulthood mental health disorders has been well documented worldwide, with prevalence rates ranging from 8-57% in population studies (Patel et al., 2007). The prevalence rates for adolescents and YAs vastly exceed those reported in global epidemiological studies measuring 12-month prevalence rates of anxiety, anxiety-related, and mood disorders (Bandelow & Michaelis, 2015; Hasin et al., 2018; Kessler et al., 2005; Ruscio et al., 2017). YA mental health vulnerability is similarly reflected in psycho-oncology (Lang et al., 2015; McDonnell et al., 2015; Park & Rosenstein, 2015; Stava et al., 2006). Examining diverse samples of cancer patients, younger participants, classified as those less than 50 years old, report higher prevalence rates of depression and anxiety across cancer diagnoses (Linden et al., 2012). Moreover, in large, heterogeneous samples of adults with cancer, younger age has been identified as a risk factor for experiencing trauma related to cancer (Abbey et al., 2015; Nipp et al., 2018). YAs may be particularly vulnerable to mental health symptoms. The developmental stressors associated with this stage of life also overlap with the age of onset of anxiety and mood disorders most commonly occurring during late adolescence and young adulthood (Kessler et al., 2007).

In Australia, investigators utilized the Cancer Survival Study cross-sectional data to examine quality-of-life, health behaviours, and psychological well-being in a sample of YAs (n=58) six months after diagnosis (Hall et al., 2012). Outcomes were measured using the European Organization for Research and Treatment of Cancer Quality of Life Questionnaire, version 3 (EORTC QLQ-C30), and Supportive Care Needs Survey-Short Form (SCNS-SF34), in addition to questions regarding health behaviours. Responses by YAs with cancer were compared to general population data for YAs nationally to contextualize the outcomes, and adults with cancer 64 years or older who had also completed the Cancer Survival Study. YAs who were six months post-diagnosis noted significant impairments in self-reported psychosocial functioning concerning sexuality, healthcare navigation, informational needs, and financial distress, compared to older adults matched for sex and cancer type. These differences further illustrate emerging and lasting psychological reactions to cancer diagnosis for individuals within this population.

De and colleagues conducted a systematic review and meta-analysis to quantify the presence of mental health disorders among YAs with cancer and identify increased risk due to cancer (De et al., 2020). The mental health concerns reported were assessed with measures validated against diagnostic criteria, and included anxiety, mood or substance use disorders. Four studies met the criteria for participants diagnosed in the YA age range. Studies examining mood outcomes reported that 17.8% of YA met clinical criteria for a mood disorder and had increased likelihood of depression compared to sibling control, and increased likelihood of antidepressant use than population data. Similarly, YA testicular cancer survivors had an increased likelihood of substance use disorders compared to their matched siblings. Meta-analysis of results across studies demonstrated an increased risk of developing anxiety and mood disorders for YAs with cancer. This study provides an overview of the limited literature, reflecting increased mental health risks of this population. It suggests that, beyond belonging to an already vulnerable demographic, YAs with cancer are an exceedingly at-risk population.

Individual studies looking at less stringent diagnostic criteria have reinforced these findings. Using data from the National Health Interview Surveys in the U.S., Kaul et al. compared a sample of YAs diagnosed with cancer in the last five years (n=875) to matched peers to evaluate the prevalence rates of distress for these populations (Kaul et al., 2017). The prevalence of moderate and severe distress in cancer survivors was 23% and 9%, respectively, compared to 17% and 3% in their sex, age, race and ethnicity, and geographically matched peers. By controlling for the influence of demographic factors, Kaul et al.'s findings further illustrate the additional risk experienced by YAs with cancer. Additionally, within this sample, 52.2% of YAs with cancer with severe distress, 74.7% with moderate, and 94.2% with low distress had not received professional mental health help within the last year. While it is difficult to ascertain the direction of this relationship, this reflects further severe psychological consequences for YAs with cancer.

Cancer diagnoses may compound mental health risks for YAs. Nikbakhsh et al. used survey data from participants with diverse cancer diagnoses (n=150) to determine prevalence rates of anxiety and depression in a sample of patients (Nikbakhsn et al., 2014). The relationship between cancer type and depression and anxiety was significant, with a high prevalence of mental health symptoms reported by participants with stomach and breast cancer. Breast cancer is among the most common cancer diagnoses for YAs (American Cancer Society, 2020); therefore, diagnosis-specific risk factors for mental health have important implications for YAs with cancer.

Long-Term Mental Health Consequences of Cancer in Young Adults

Mental health consequences of cancer are among the long-term implications that extend beyond curative treatment. These patterns are demonstrated in a year-long longitudinal study conducted by McDonnell and colleagues that assessed the relationships between cancer-related worry and posttraumatic growth in a sample of 153 YA cancer survivors (McDonnell et al., 2018). Based on qualitative data, researchers developed seven questions to assess participants' worry. Scores of worry remained consistent across time, with greatest concerns reported for future health. Participant responses further reflect the stable nature of psychological symptoms over time for YAs with cancer particularly for worry and preoccupation with future concerns.

Similarly, a study of child, adolescents and YA cancer survivors with intracranial germinoma (n=33, median age =18) collected long-term data regarding neurological functioning and quality of life over time (Martens et al., 2014). Outcomes were collected through physical examinations, patient interviews, medical chart review, and completion of the EORTC QLQ-C30. Participant measures of quality of life were compared to normative data for healthy controls, with follow-up ranging widely, with an average of 12 years. Compared to healthy controls, patient-participants reported significantly worse quality of life, with the most considerable social, emotional, and role functioning impairments. This study demonstrates that psychosocial consequences and subsequent impairments may not resolve over time.

In addition to poorer quality-of-life, mental health symptoms, including anxiety, depression and posttraumatic stress, persist in YAs with cancer years post-diagnosis (Ander et al., 2016; Seitz et al., 2010). In a cross-sectional survey, Seitz et al. examined current mental health symptoms in a sample of YAs (n=820) diagnosed with cancer at least five years prior and compared them to patient-recruited controls and population data (Seitz et al., 2010). Patient-participants who exceeded clinical criteria on measures were further assessed via telephone interviews to determine the accurate prevalence of mental health disorders in this population. Through interviews, YA male and female cancer survivors also reported a significantly higher prevalence of posttraumatic stress (5.7% vs. 2.1%), depression (14.9% vs. 9.3%), and anxiety disorders (16.5% vs. 11.0%) compared to peers. The lasting psychological implications of cancer for YAs is also demonstrated in a study conducted by Ander et al. (2016). A diverse sample of patients (n=67) diagnosed in adolescence and YAs age 13 to 19 was assessed across eight time-points, beginning immediately after diagnosis, throughout their first year, several years following and up to 10 years post-diagnosis. Symptoms and functioning fluctuated over time with an initial reduction in impairments, which rose again by the 10-year assessment point. Mental health and vitality declined between assessments at 18-months and 10-years post-diagnosis and most notably, participants did not experience improvements in overall social and emotional functioning and physical health compared to baseline at any point during the 10 years after their diagnosis.

The value of psychosocial care within oncology to improve outcomes and reduce healthcare costs underscores the systemic importance of applying this to the YA population. Moreover, limited attention and emphasis on YAs in current literature as an essential and distinct demographic for exploration emphasizes the immediate need for research that addresses the intersection between developmental and mental health vulnerabilities for this population.

1.5 The Importance of Patient-Oriented Research and Knowledge Translation for Young Adults

It takes 17 years, on average, for academic research to be integrated into clinical practice (Morris et al., 2011). Consequently, YAs likely to benefit from existing research are not profiting from current findings. Given the developmental and mental health vulnerabilities for YAs with cancer, patient engagement, including patient-oriented research (POR) and knowledge translation (KT), can help address some of the research implementation obstacles. The Canadian Institutes of Health Research have conceptualized patient engagement as meaningful and active collaboration across many healthcare domains, including governance, priority setting, research, and knowledge translation (Canadian Institutes of Health Research, 2019). Specifically, POR represents a spectrum of patient engagement throughout the research process; patients taking on research roles, providing input regarding priorities and outcomes, to apply this information to enhance healthcare. POR principles can be simultaneously applied to enhance research quality and access for YAs with cancer.

The Value of Patient-Oriented Research

Patient-oriented research has successfully illustrated how patient engagement can improve the applicability and appropriateness of research studies (Cashman et al., 2008; Chiu et al., 2013; Edwards et al., 2011; Forsythe et al., 2015). Given the developmental nuances for YAs, this approach to research could help support autonomy and individual identity milestones, particularly for YAs transitioning from pediatric to adult oncology. Nationally within Canada, there is conflicting perspective regarding adolescent decision-making capacity. For YAs who do not meet the age of majority (either 18 or 19, depending on the province), shared decision-making with the family and healthcare practitioners is thought to be the best approach (Coughlin, 2018). A systematic review (n=21)was undertaken to gauge and identify factors that impact the involvement of adolescents and YAs in their healthcare (Pyke-Grimm et al., 2019). Lacking information is considered a barrier for decision-making, and YAs demonstrated a preference for clear medical information. Conversely, having more experience in coping with illness and greater overall maturity were found to contribute an increased engagement in decision-making. Considering the limited role that younger YAs may play in informing treatment decisions, engaging them in research may help share their unique perspective and build autonomy in a developmentally and treatment-sensitive way. Additionally, participating in research can assist YAs with building the capacity to understand scientific health research and support them in addressing their informational needs, improving their engagement in treatment decision-making Overall, the involvement of YAs in POR creates opportunities for researchers to incorporate the patient experience to enhance the applicability and appropriateness of the research conducted and enhance communication with YA consumers.

The Value of Knowledge Translation for Young Adult Research

POR has illustrated the value of patient engagement in the development and facilitation of research studies; however, studies often lack an explanation of patient engagement in translating study findings (Forsythe et al., 2015). KT represents a research partnership between the target users (i.e. patients, stakeholders) and researchers, using their expertise of problems and knowledge gaps, understanding of context, implementing findings, and methodological and empirical strategies, respectively (Graham et al., 2006;

Kothari et al., 2017). Kazanjian and colleagues used the Knowledge Exchange-Decision Making Model to identify barriers impeding the successful implementation of a psychosocial program for cancer survivors across Canada (Kazanjian et al., 2012). Similarly, Street and colleagues illustrated that education-centred KT strategies like a brochure or interactive multimedia program can increase treatment knowledge for younger patients by enhancing their ability to engage in meaningful treatment discussions with their physicians (Street et al., 1995). Addressing service barriers and increasing engagement illustrates how KT's application could address the challenges of effectively reaching this population.

The integration of KT into YA cancer care practices also enhances healthcare quality by having YA priorities reflected in treatment outcomes (Zebrack et al., 2007). Nielsen et al. created a “shared care program" for newly referred cancer patients, and two hundred and forty-eight participants were randomly assigned to the program or care as usual (Nielsen et al., 2003). The program included knowledge transfer tools, enhanced communication channels, and active patient involvement to share patient healthcare responsibility. Communication of pertinent information between patients and healthcare practitioners participating in the program contributed to more positive appraisals of care, and patients felt their care was more coordinated and had increased contact at follow-up. Considering that YAs with cancer engage in less healthcare follow-up (Galan et al., 2017), POR and KT may address some of the challenges associated with treating this population. Integrating YA patients in their care may improve the translation of information to patients, and subsequent follow-up and care monitoring.

An Example in Practice: *The YACPRIME Study*

POR and KT's ability to enhance the quality and applicability of research, increase the speed at which results are disseminated and implemented into practice, and support the tailoring and efficacy of services for YAs with cancer motivated the undertaking of the YACPRIME Study. YAs have been described as the forgotten generation within cancer care, with the focus generally on pediatric and adult oncology. Partnership with Young Adult Cancer Canada (YACC), a not-for-profit national organization, working to "support young adults living with, through, and beyond cancer…[providing connections to] peers, [and] bridging …isolation" offered an opportunity to connect with patient groups not otherwise captured in the healthcare system (*Young Adult Cancer Canada*, 2014).

The Patient Engagement in Research (PEIR) Framework was created by Hamilton and colleagues to provide an empirically structured framework to improve POR (Hamilton et al., 2018). Researchers reviewed data collected from patients interviewed about their participation in research and analyzed emerging themes related to active engagement in research. These themes formed the theoretical framework, which was then applied to a review of 18 studies with similar examination patient involvement. Eight key principles related to patients' positive engagement in research were identified: 1) having procedural requirements that managed the inclusion of patients; 2) ensuring participation was convenient for patients; 3) enabling patients to contribute to the scope, direction or outcomes meaningfully; 4) team interactions are respectful and convey trust in patient-partners; 5) having a research environment that is positive and inclusive of patients, demonstrating receptivity to patient expertise; 6) patients are offered informational and financial support to engage in research actively; 7) patients feel valued by team members, with appropriate recognition of their contributions; and 8) that patient participants see the impact of their participation and experience personal benefits from their participation.

The YACPRIME study offers an excellent example of this framework in practice. Within the procedural components requirement of the PEIR framework, the development of this study benefited from direct input from the organizational staff at YACC, one of whom is a YA cancer survivor. YACC participated actively in each team meeting, selected project goals and research questions relevant to the patient population, and acted as a liaison to their more extensive YA cancer network. Convenience within the PEIR framework refers to patients' ability to dictate their involvement and contributions. The researchers defaulted to YACC members to determine their capacity for involvement in selecting questions, materials, recruitment, analysis and dissemination of the study. Quality team interactions require respectful rapport and effective communication style, and for effective implementation of the PEIR framework, patients also need to feel valued as contributors. In the YACPRIME Study, the success of the team interactions was reflected by the amount of input patient partners provided, illustrating their comfort with the team dynamics. Further, as an illustration of how YACCs expertise was valued, they were always consulted prior to presenting research findings to ensure the tone reflected the organizational goals. Another theme of the PEIR framework is providing information and financial support to the partners. Grant funding was secured to support patient partners in attending and presenting at national and international conferences, and emphasis was placed on navigating the research process and training patients on how to interpret findings. The final component for the PEIR Framework was to ensure benefits for patient partners, specifically the ability to see the impact of their participation on others, organizations, and resources and gain skills and enhance their knowledge. Within the YACPRIME study, patient and organizational partners were able to generate knowledge that changed how YACC offered programs to meet YAs support and informational needs. Additionally, members of YACC gained insight into the research process, including how to interpret research findings, present study findings at research conferences and contribute to academic articles, which in turn contributed to greater advocacy.

1.6 Summary and Objectives

YAs with cancer face significant developmental challenges resulting from cancer diagnosis during this stage of life. To adequately address the different needs of YAs, POR that characterizes population-specific risk factors and illustrates the lasting psychological consequences of cancer is needed. Based on patient collaboration with YACC, the following research objectives were chosen to better understand the psychological challenges experienced by YAs and identify increasingly vulnerable YAs within this community.

The primary research objectives of this thesis are as follows:

1. Compare levels of distress in YAs with cancer to non-cancer peers matched on age, sex, and education and examine which factors are related to an increased likelihood of experiencing high levels of distress in YAs with cancer.
2. Document the prevalence and examine factors associated with a specific type of distress, fear of cancer recurrence, in YAs with cancer.

The two studies included in this investigation which reflect these objectives have been published and their respective references are included at the outset of each chapter.

Co-author contributions reflect support with statistical analysis, insights into the existing literature in the field and minor suggestions for editing.

Chapter 2: Prevalence and Factors Associated with High Levels of Distress in Young Adult Cancer Survivors Compared to Matched Peers[1]

---

[1] **Chapter Reference for Publication:**

Lane, B., Fowler, K., Eaton, G., Chalifour, K., & Garland, S. N. (2020). Prevalence and factors associated with high levels of distress in young adult cancer survivors compared to matched peers. Support Care Cancer. doi: https://doi.org/10.1007/s00520-020-05785-3

2.1 Abstract

OBJECTIVE: Young adulthood can be a difficult period of development and disruption of age-related milestones can impact psychological well-being. This study examined whether psychological distress differs in young adult (YA) cancer survivors compared to their non-cancer peers, and identified factors related to high distress in YA cancer survivors.

METHODS: Canadian YAs (n=448) who completed the YACPRIME Study, diagnosed with cancer between the ages of 15-39, were compared to age, sex, and education-matched controls (n=448) randomly sampled from the 2012 Canadian Community Health Survey – Mental Health. The primary measure was the Kessler Psychological Distress Scale (K10). Groups were compared using independent samples t-tests and chi-square tests of independence. Logistic regression was used to examine the factors associated with high (moderate/severe) distress for YA cancer survivors.

RESULTS: YA cancer survivors reported significantly higher distress than their matched peers (24.89 vs. 15.75; *p* <.0005). In the multivariate model, greater years of education was associated with decreased likelihood of high distress [Adjusted Odds Ratio (AOR)=0.84, p=.001]. Compared to those working, being in school (AOR=6.81, p=.003) or not in school/working (AOR=4.13, p<.0005) were associated with higher distress. Psychological factors associated with high distress in YA cancer survivors included body image dissatisfaction (AOR=1.09, p<.0005), poor social support (AOR=5.19, p=.011), and elevated fears of cancer recurrence (maladaptive: AOR=6.39, p=.001; clinical: AOR=12.31, p<.0005).

CONCLUSIONS: YA cancer survivors experience significantly greater distress than their non-cancer peers. This distress is associated with modifiable factors such as body image dissatisfaction, social support, and fear of cancer recurrence, illustrating key areas for intervention.

2.2 Introduction

Psychological distress describes the collective unpleasant or painful psychosocial responses that impair effective coping with cancer. Psychological distress can present as depression, anxiety, somatic symptoms, impaired relationships, and existential concerns (Howell & Olsen, 2011). The pervasiveness of distress in cancer, coupled with under-reporting due to inaccurate assessment, motivated the adoption of distress as the sixth vital sign of patients' health and well-being (Bultz & Carlson, 2005). Initial studies suggest that young adults (YAs) experience more prevalent and severe levels of distress (Lang et al., 2015; Wang et al., 2014), compared to other aged patients and their non cancer peers, indicating that cancer in young adulthood may come with additional psychosocial burden (Kaul et al., 2017). Generally, young adulthood is a complex developmental stage, with an emphasis on transition, autonomy, and individual identity (Zirkel & Cantor, 1990), and is also the age of onset for many mood and anxiety disorders (Kessler et al., 2007). Compared to peers, YA cancer survivors are more likely to report poor perceived health, and anxiety (15.1% vs. 5.4%) and mood disorder diagnoses (14.8% vs. 5.7%), a difference not observed among the older adults (Lang et al., 2018). Unfortunately, this study was limited by estimating the prevalence of mental health concerns using previous mental health diagnoses and perceived mental health with a single item. Further, patients with metastatic cancer were excluded from this study, while childhood cancer survivors who were currently within the YA range were included. As such, more research is needed to draw more definitive conclusions about the psychological consequences of being diagnosed with cancer in young adulthood.

There is evidence that other demographic, disease, and physical and psychological characteristics are related to higher levels of distress. Sex may partially account for differences, as females are more likely to report psychosocial concerns as a result of a cancer diagnosis and experience a higher prevalence of severe distress (Koyama et al., 2016; Wang et al., 2014). YAs also often face significant financial stress as a result of cancer and report more considerable financial difficulties than older adults (Hall et al., 2012). Disease severity and somatic symptoms (Koyama et al., 2016), uncertainty regarding treatment (Neville, 1998), and fears of recurrence (Lebel, Beattie, et al., 2013) have also been associated with higher levels of distress. Further, evidence also suggests poorer physical health, sleep disturbances (Daniel et al., 2016; Mehnert et al., 2018), body image concerns (Koyama et al., 2016), and social isolation (Brett et al., 2014), may contribute to the increased prevalence of distress in YAs. Studying the impact of age in connection with other demographic, clinical cancer, and psychosocial variables will provide essential insights into how to address distress for YA cancer survivors.

To determine the psychosocial burden of cancer in YAs, the primary aim of the current study was to compare YA cancer survivors and non-cancer peers matched on age, sex, and education using a global measure of distress. The secondary aim of this study was to examine which demographic, cancer, and psychosocial factors are related to an increased likelihood of experiencing high levels of distress within the YA cancer survivor sample.

2.3 Methods

Participants

This study utilized data from the Young Adults with Cancer in their Prime (YACPRIME) study. Participants had to have been diagnosed with cancer between the ages of 15 and 39 (Adolescent and Young Adult Oncology Progress Review Group, 2006), reside in Canada, and currently be 19 years or older, in accordance with policy and ethics approval from Memorial University's Interdisciplinary Committee on Ethics in Human Research (ICEHR). Participants were recruited through direct emails, media promotion, online advertisements, social media posts, and referrals from healthcare professionals. Data from this survey were collected between June 2017 and March 2018 using the platform Survey Monkey (https://www.surveymonkey.com/). Participants completed a digital consent form prior to accessing the survey. Individuals could provide contact information separately to be entered to win an online gift card valued at $25.

This project was created in collaboration with Young Adult Cancer Canada (YACC), a national network dedicated to providing support and advocacy for YA cancer survivors. Discussions with members of YACC were held to derive patient objectives and concerns for investigation in the present study. YAs reported often feeling different and isolated from their peer as a result of cancer and treatment (D'Agostino & Edelstein, 2013). Therefore, the focus of this study was to address YAs questions by helping to understand how their psychosocial needs compare to their peers and to ultimately reduce self-stigma associated with their different experiences of distress.

Six hundred and twenty-two individuals completed the YACPRIME study; however, for the present study, we restricted the sample to those currently 39 years or younger (n = 508). An additional 51 participants were excluded that did not respond to all 10-items that comprised the dependent variable. We were not able to identify an appropriate non-cancer peer match for nine additional participants. The remaining sample was comprised of 448 YA cancer survivors and 448 non-cancer peers. Participants in the YACPRIME survey were asked to report both their sex and gender. Of the 448 participants, only six endorsed "Other"; three participants identified as gender fluid or queer, one identified as femme, and two participants did not indicate their gender. Further, in the Canadian Community Health Survey (CCHS) dataset there was no variable for gender, which would have prevented us from being able to identify a population match. Seeing that we did not want to exclude participants from the analysis on the basis of belonging to a gender minority group, sex was used as the variable for the analysis and here forth reference to female refers to sex.

Case Matching

Case matching was used to create a comparison sample with data obtained from the 2012 CCHS - Mental Health (CCHS-MH) (*Canadian Community Health Survey - Mental Health (CCHS)*, 2013). The data from the 2012 survey were used as this was the last time the Kessler Psychological Distress Scale (K10) was administered nationally by Statistics Canada. CCHS-MH participants were 15 years of age or older, living in any province, and excluded individuals living on reserves, members of the armed forces, or in institutionalized settings. The CCHS-MH was cross-sectional and sampled respondents based on sex, age, and location, via computer-assisted interviewing. For the current study, additional participants were excluded if they responded affirmatively to having cancer, or having received a previous cancer diagnosis.

To match participants, frequencies of age, sex, and educational attainment were calculated for the YACPRIME participants. Controlling for these characteristics, all possible CCHS participants who met the demographic criteria were isolated and then randomly sampled to reflect the same frequencies as the YACPRIME participants. The CCHS non-cancer peers were merged with the YACPRIME dataset to compare responses between groups.

Dependent Variable

The K10 was used to measure participants' distress, symptoms of anxiety, and depression, within the last month (Andrews & Slade, 2001). The K10 consists of 10 items rated on a 5-point Likert scale, which for this administration, ranged from 1 to 5 ("None of the time" to "All of the time") for each item and provided an overall measure of distress between 10 to 50. Total scores < 20 do not indicate distress, scores ranging from 20-24 are suggestive of mild distress, scores from 25-29 are indicative of moderate distress, and scores greater than or equal to 30 suggest severe distress (Andrews & Slade, 2001). The K10 has demonstrated adequate sensitivity and specificity in identifying individuals who meet the criteria for anxiety and affective disorders, as well as the ability to discriminate between individuals without disorders (Andrews & Slade, 2001). The K10 has been utilized with an Australian adolescent and YA population (n=196) to measure symptoms of anxiety and depression (McCarthy et al., 2016). The K10 was utilized across the YA cancer survivor and matched peer samples.

Given the study's objectives, participants with none or mild distress scores were classified as low distress, and participants with moderate and severe distress scores were classified as high distress. Cronbach's alpha was 0.90 within the sample.

Independent Variables

Relevant sociodemographic variables (age, sex, education, income, relationship status, living arrangement, parental status, race/ethnicity) for both samples and factors related to participants' cancer diagnosis and treatment were collected through self-report and chosen based on theoretical support and patient and stakeholder collaborator input (Kazak et al., 2010).

We used a single item from the Short-Form Health Survey 12 (SF-12) as an estimate of perceived health quality for both samples. On this item, a score of 1 refers to "excellent" health and a score of 5 reflects "bad" health (Ware et al., 1996).

Self-reported sleep quality within the last month was evaluated using the Pittsburgh Sleep Quality Index (PSQI). The PSQI includes 19 items, and the total score ranges from 0-21 with higher scores indicating worse sleep quality, using a total cutoff score of > 5 to indicate impaired sleep quality (Buysse, 1989). This measure has sufficient construct validity and internal consistency in the assessment of sleep quality in individuals with cancer and has been used in an adolescent and YA population (Daniel et al., 2016). Cronbach's alpha was 0.82 within the sample.

Participants' body image dissatisfaction as a result of cancer was evaluated using the Body Image Scale (BIS), which has 10 items rated within the past week reflecting affective, behavioral, and cognitive domains (Falk Dahl et al., 2010). Acceptable measures of internal consistency, reliability, and clinical validity have been demonstrated for this measure (Melissant et al., 2018). Cronbach's alpha was 0.92 within the sample.

Perceived social support was measured using the Medical Outcome Study Social Support Survey (MOS-SSS) (Sherbourne & Stewart, 1991). The MOS-SSS is a 19-item scale, and scaled scores range from 0-100, with higher scores indicating better social support (Sherbourne & Stewart, 1991). The mean total of perceived social support in a chronic illness population and standard deviation reported in the validation of the measure was used to categorize responses ($M = 70.1$, $SD = 24.2$) as poor (≤ 45.9), average (46.0-94.2) and high perceived social support (≥94.3) (Sherbourne & Stewart, 1991). The MOS-SSS has adequate reliability, and has been validated in cancer and chronic illness populations (Sherbourne & Stewart, 1991). Cronbach's alpha was 0.95 within the sample.

Participants' fears of cancer recurrence were measured using the nine-item Fear of Cancer Recurrence Inventory-Short Form (FCRI-SF) (Simard & Savard, 2015). Scores on the FCRI-SF can be used to measure the severity of FCR; scores of < 16 are suggestive of minimal levels of FCR, scores of 16-21 are suggestive of maladaptive levels of FCR, and scores of ≥22 indicate clinically significant levels of FCR. These cutoff scores have demonstrated high sensitivity and adequate specificity (Fardell et al., 2018; Simard & Savard, 2015). Cronbach's alpha was 0.85 within the sample.

Statistical Analysis

Descriptive statistics were used to characterize the sample's demographic and clinical characteristics. An independent samples t-test was used to examine differences in distress between YA cancer survivors and the matched-sample. Examination of the data for the non-cancer YAs revealed that K10 scores were positively skewed 1.90 (standard error = 0.12) with a positive kurtosis of 4.90 (standard error = 0.23). There was also a slight positive skew for the YA cancer survivors (0.39, standard error = 0.12) but kurtosis was normal (-0.28, standard error = 0.23). Given the large, equal sample size for cancer and non-cancer conditions, and the desire to obtain a diverse population, the robustness of the test will account for these violations (Laerd Statistics, 2015). Participants were also compared on demographic variables consistently measured across groups, to further illustrate population differences and similarities.

Binomial logistic regression was used to examine factors related to increased likelihood of experiencing high levels of distress in the YA cancer survivor group. Variables with established clinical cutoffs were used categorically to help inform clinical decision making and ease interpretation and communication of results to patient partners and stakeholders. Univariate binomial logistic regressions were used to identify independent variables associated with high distress (scores of ≥25 on the K10 (Andrews & Slade, 2001)). Covariates with p values <.10 were then simultaneously entered into a multiple binomial logistic regression model (Bursac et al., 2008). Linearity of the continuous variables with respect to the dependent variable were assessed via the Box-Tidwell procedure (Box & Tidwell, 1962). A Bonferroni correction was applied using all 21 terms in the model resulting in statistical significance being accepted when $p < .00238$. All continuous independent variables were found to be linearly related to the dependent variable. Variables in the multivariable model were assessed for multicollinearity using linear regression (Hair et al., 2006). All variables had a variance inflation factor <2, demonstrating no violations of multicollinearity. In examining casewise diagnostics for outliners, five cases had standardized residual scores that exceeded two standard deviations and were removed from the model. Analyses were conducted using SPSS Version 27. All tests were two-sided, with $p < 0.05$ indicating statistical significance for the logistic regression analyses.

2.4 Results

Demographics

Participants with cancer had a mean age of 32.22 years (*SD* = 4.72). The majority of participants were Caucasian (88.2%), female (86.8%), in committed relationships (67.0%), and graduated from post-secondary school (68.8%).

The most commonly reported cancer diagnoses/categories included blood cancers (27.9%), breast cancer (24.8%), and female genitourinary cancers (11.1%). Participants reported an average time since diagnosis of 3.78 years (*SD* = 3.83) and the most common cancer stages were II (29.0%) and III (23.2%). Table 1 and Table 2 provide further descriptive characteristics of the YA cancer sample.

Matched Sample Comparison

Matching participants produced equivalent groups with no significant differences in age, sex, and education. Independent samples t-tests were used to compare differences in distress and perceived health quality for YAs with and without cancer. Distress was significantly higher for YA cancer survivors ($M = 24.89$, $SD = 7.76$) than YAs without cancer ($M = 15.75$, $SD = 5.77$), t (825.862) = 19.995, $p < .0005$, Cohen's $d = 1.336$. Similarly, perceived health quality was worse for YA cancer survivors ($M = 3.04$, $SD = 0.96$) than YAs without cancer ($M = 2.17$, $SD = 0.93$), t (837) = 13.341, $p < .0005$, Cohen's $d = 0.925$.

Chi-square tests of independence were conducted to determine whether there was an association between participant group (YA cancer survivors vs. matched peers) and marital status, living arrangement, and personal income, respectively. There was a statistically significant association between marital status and cancer diagnosis, $\chi^2(2) = 17.294$, $p < .0005$ (Table 1). Although the association was small (Cramer's $V = .139$) (Cohen, 1988), YA cancer survivors were more likely to be in a committed relationship (Odds ratio [OR] = 1.632) and matched peers were more likely to be divorced or separated (OR = 2.531). The association between living arrangement and cancer diagnosis was also statistically significant, $\chi^2(6) = 160.228$, $p < .0005$. YA cancer survivors were 8.6 times more likely to be unattached and living with others (OR = 8.611) and 1.8 times more likely to be living with parent(s) and sibling(s) (OR = 1.838) than matched peers, and the association was moderately strong (Cramer's $V = .424$) (Cohen, 1988). In contrast, matched peers were 3.4 times more likely to report living with a partner (OR = 3.355) and 3.5 times more likely identify as a single parent (OR =3.553), than YA cancer survivors. There was a statistically significant association between personal income and cancer diagnosis, $\chi^2(2) = 141.388$, $p < .0005$, with YA cancer survivors being more likely to report an annual personal income of < \$20,000 (OR = 7.500) and between \$20,000-\$40,000 (OR = 1.987) than matched peers, with a moderately strong association (Cramer's $V = .404$) (Cohen, 1988). While YAs without cancer were 5.5 times more likely to have an income of \$40,000 annually than YA cancer survivors (OR = 5.474).

Table 1. *Demographic information and comparison of matched sample.*

Variable		YACPRIME (cancer)	CCHS (no cancer)	Test statistic	Effect Size Comparison	Effect Size
Age				$\chi^2(3) = 0.000$ $p = 1.000$		
	20-24	33 (7.4%)	33 (7.4%)			

25-29	83 (18.5%)	83 (18.5%)			
30-34	170 (37.9%)	170 (37.9%)			
35-39	162 (36.2%)	162 (36.2%)			
Sex					
Male	59 (13.2%)	59 (13.2%)	$\chi^2(1) = 0.000$ $p = 1.000$		
Female	389 (86.8%)	389 (86.8%)			
Education			$\chi^2(3) = 0.000$ $p = 1.000$		
< Secondary school	11 (2.5%)	11 (2.5%)			
Secondary school graduate	9 (2.0%)	9 (2.0%)			
Some post-secondary	120 (26.8%)	120 (26.8%)			
Post-secondary graduate	308 (68.8%)	308 (68.8%)			
Marital Status			$\chi^2(2) = 17.294$, $p < .0005$		
In a committed relationship	297 (67.0%)	248 (55.5%)		YAC:CCHS	1.632*
Divorced or separated	17 (3.8%)	41 (9.2%)		CCHS:YAC	2.531**
Single	129 (29.1%)	158 (35.3%)		CCHS:YAC	1.331
Living Arrangement			3		
Unattached, living alone	72 (16.1%)	92 (21.7 %)		CCHS:YAC	1.451
Unattached, living with others	139 (31.0%)	21 (5.0%)		YAC:CCHS	8.611***
Living w/ spouse/partner	25 (5.6%)	70 (16.5%)		CCHS:YAC	3.355**
Parent w/ spouse/partner, children	133 (29.7%)	154 (36.4%)		CCHS:YAC	1.356
Single parent w/ children	17 (3.8%)	52 (12.3%)		CCHS:YAC	3.553**
Living with parent, with/without siblings	62 (13.8%)	34 (8.0%)		YAC:CCHS	1.838*
Other	11 (4.9%)	0 (0.0%)			

Personal Income			$\chi^2(2)$ = 141.388, *p* < .0005		
< $20,000.00	152 (34%)	27 (6.4%)		YAC:CCHS	7.500***
$20,000.00 to less than $40,000.00	103 (23.0%)	55 (13.1%)		YAC:CCHS	1.987*
$40,000.00 or greater	192 (43.0%)	338 (80.5%)		CCHS:YAC	5.474***
Perceived Health Quality *(higher scores refer to worse health)*	3.04 (*SD* = 0.96)	2.17 (*SD* = 0.93)	*t* (837) = 13.341, *p* <.0005		0.925***
Psychological Distress (K10)	24.89 (*SD* = 7.77)	15.75 (*SD* = 5.78)	*t* (894) = 19.995, *p* <.0005		1.336***

* Small effect size, ** Medium effect size, *** Large effect size

Table 2. *Additional sociodemographic variables for young adults with cancer sample.*

		Frequency (%) n = 448
Race/Ethnicity		
	Caucasian	395 (88.2%)
	Asian	15 (3.3%)
	Multi-racial/Ethnic Identity	16 (3.6%)
	Aboriginal/First Nations	11 (2.5%)
	Other	11 (2.5%)
Children		
	No children	296 (66.1%)
	1+ children	152 (33.9%)
Years of Education (Mean, SD)		17.13 (3.08)
Cancer Diagnosis		
	Breast	111 (24.8%)
	Female Genitourinary	48 (10.7%)
	Male Genitourinary	6 (1.3%)
	Thyroid	37 (8.3%)
	Blood Cancers	125 (27.9%)
	Head & Neck	41 (9.2%)
	Gastrointestinal	39 (8.7%)
	Skin	114 (3.1%)
	Multiple Types	5 (1.1%)
	Other	22 (4.9%)

Cancer Stage	
Stage 1	59 (13.2%)
Stage 2	130 (29.0%)
Stage 3	104 (23.2%)
Stage 4	62 (13.8%)
Don’t Know	60 (13.2%)
Not Applicable	34 (7.6%)
Treatment Status	
Not on treatment	298 (66.5%)
Currently on treatment	150 (33.5%)
Metastatic Cancer Status	
No	349 (77.9%)
Don’t Know	38 (8.5%)
Yes	61 (13.6%)
Time Since Diagnosis, Mean Years (SD)	3.78 (3.83)
< 2 years	149 (32.6%)
2 – 4 years	167 (37.2%)
5+ years	130 (29.8%)
Missing	2 (0.4%)
Psychological Distress	
No clinical distress	27.2%
Mild clinical distress	24.3%
Moderate clinical distress	20.5%
Severe clinical distress	27.9%

Factors Associated with High Levels of Psychological Distress

Collectively, 72.8% of YA cancer survivors exceeded the clinical cutoff of 20 for mild distress on the K10 (Table 2). Specifically, 24.3% reported mild distress (20-24), 20.5% of participants reported moderate distress (25-29), and 27.9% reported severe distress. Separate univariate binomial logistic regression models were used to identify significant independent factors associated with high distress. For complete univariate analysis see Table 3. All significant independent variables were entered into a multivariate binomial logistic regression. The logistic regression model was statistically significant, $\chi^2(18) = 164.072$, $p < .0005$, and these predictors explained 51.6% of the variance (Nagelkerke R^2) in high distress. The multivariate model correctly classified

78.2% of cases; sensitivity was 77.7%, and specificity was 78.7%, while the positive predictive and negative predictive values were 78.2% and 78.2%, respectively.

In the multivariate model, participants who reported were not currently working or enrolled in school (Adjusted Odds Ratio [AOR] = 4.134 [2.060, 8.296], *p* < .0005), or identified as students (AOR = 6.813 [1.942, 23.906], *p* =.003), were more likely to experience high distress than individuals who reported being employed. Similarly, participants with greater body image dissatisfaction as a result of cancer were more likely to experience high distress (AOR = 1.088 [1.047, 1.130, *p* =.0005) than those with less dissatisfaction. Compared to individuals with high-perceived social support, only those individuals with poor perceived social support (AOR = 5.191 [1.468, 18.350], *p*=.011) were more likely to experience high distress. Fear of cancer recurrence of any severity remained significantly related to high distress. Individuals who reported maladaptive levels and clinical levels of fear of cancer recurrence were six times (AOR = 6.386 [2.071, 19.696], *p* = .001) and almost 12 times more likely to experience high distress (AOR = 12.311 [4.226, 35.863], *p* <.0005), than individuals with minimal levels. At the multivariate level, living arrangement, income, metastatic cancer status, treatment status, time since diagnosis and sleep were no longer significantly associated with distress.

Table 3. *Factors associated high levels of psychological distress (K10 scores of ≥ 24) in young adults with cancer.*

	Univariate Logistic Regression Analysis		Multivariate Logistic Regression Analysis	
	Odds Ratio [95%CI]	*p*	Adjusted Odds Ratio [95%CI]	*p*
				<.0005*
Age	0.980 [0.942, 1.020]	.321		
Sex				
Male (Ref)	1			
Female	1.224 [0.706, 2.124]	.472		
Relationship Status				
Single (Ref)	1			
In a relationship	0.743 [0.500, 1.105]	.142		
Children				
No children (Ref)	1			
1+ children	1.191 [0.805, 1.761]	.383		
Years of Education	0.868 [0.813, 0.927]	**<.0005**	0.837 [0.757, 0.927]	**.001**
Living Arrangement				
Alone (ref)	1		1	
With others	0.571 [0.357, 0.915]	**.020**	0.527 [0.235, 1.182]	.120
Current Employment Status		**<.0005†**		
Working part/full time (Ref)	1		1	
In school part/full time	2.341 [1.128, 4.859]	**.022**	6.813 [1.942, 23.906]	**.003**
Not working or in school	4.512 [2.781, 7.320]	**<.0005**	4.134 [2.060, 8.296]	**<.0005**
Income		**.002†**		
< $20,000 (Ref)	1		1	
$20,000 to < $40,000	0.742 [0.448, 1.226]	.244	0.726 [0.322, 1.640]	.442
$40,000 to < $60,000	0.632 [0.371, 1.077]	.091	2.249 [0.908, 5.572]	.080

$60,000 or more	0.374 [0.223, 0.626]	**<.0005**	1.218 [0.532, 2.791]	.641
Cancer Stage at Diagnosis		.260†		
Stage 1 (Ref)	1			
Stage 2	0.519 [0.278, 0.969]	**.040**		
Stage 3	0.660 [0.346, 1.259]	.207		
Stage 4	0.529 [0.257, 1.089]	.084		
Don’t Know	0.870 [0.419, 1.807]	.710		
Not Applicable	0.541 [0.231, 1.271]	.159		
Current Metastatic Cancer Status		**.025†**		
No (Ref)	1		1	
Don’t Know	2.325 [1.151, 4.693]	**.019**	2.148 [0.660, 6.991]	.204
Yes	1.522 [0.881, 2.632]	.132	0.853 [0.321, 2.271]	.751
Treatment Status				
Not currently on treatment (Ref)	1		1	
On treatment	1.579 [1.064, 2.344]	**.023**	1.236 [0.611, 2.501]	.556
Time Since Diagnosis		**.003†**		
< 2 years (Ref)	1		1	
2 – 4 years	0.768 [0.492, 1.200]	.247	0.786 [0.377, 1.639]	.521
5+ years	0.443 [0.274, 0.716]	**.001**	0.673 [0.297, 1.526]	.343
Pittsburgh Sleep Quality Index (PSQI)				
Good Sleep (≤ 5) (Ref)	1		1	
Poor Sleep (>5)	3.986 [2.305, 6.891]	**<.0005**	2.076 [0.994, 4.564]	.069
Body Image Dissatisfaction (BIS)	1.116 [1.086, 1.147]	**<.0005**	1.088 [1.047, 1.130]	**<.0005**
Social Support (MOS-SSS)		**<.0005†**		
High (94.3+) (Ref)	1		1	
Average (45.9-<94.3)	2.611 [1.268, 5.374]	**.009**	1.354 [0.498, 3.680]	.552
Poor (<45.9)	7.342 [3.134, 17.200]	**< .0005**	5.191 [1.468, 18.350]	**.011**

Fear of Cancer Recurrence – Short Form (FCRI-SF)		**<.0005†**		
Adaptive FCR (<16) (Ref)	1		1	
Maladaptive FCR (16-21)	2.971 [1.400, 6.302]	**.005**	6.386 [2.071, 19.696]	**.001**
Clinical FCR (22+)	8.953 [4.481, 17.887]	**<.0005**	12.311 [4.226, 35.863]	**<.0005**

Continuous variables were categorized based on available data, or population distribution within the sample.

† Overall significance for variables with more than two categories at the univariate level.

* Significance for the overall multivariate model.

2.5 Discussion

Distress Differences between YA Cancer Survivors and Matched Peers

YA cancer survivors experience significantly greater levels of distress and report poorer perceived health quality than their age, sex, and education matched peers. YA cancer survivors had moderate distress on average while their matched peers reported subclinical levels. Moderate scores of the K10 are associated with an approximately 30% probability of meeting DSM-IV criteria for an anxiety and/or mood disorder (Andrews & Slade, 2001). In comparison, subclinical scores reported by matched peers were associated with 3.8% prevalence for anxiety disorders and 3.0% for mood disorders. Significant differences were also noted in income and living arrangement between YA cancer survivors and their matched peers, suggesting that a diagnosis of cancer in young adulthood compromises the ability to keep pace with peers (Parsons et al., 2012; Rabin, 2019).

Factors Associated with Psychological Distress in YA Cancer Survivors

The severity of distress was largely independent of demographic and cancer variables. The only demographic variables that remained significantly associated with distress after accounting for other factors were employment status and years of education. In contrast, body image dissatisfaction, fear of cancer recurrence, and poor social support were all associated with high levels of distress. Body image dissatisfaction and changes in appearance as a result of cancer can increase distress by acting as reminders of illness, which can contribute to social isolation and feelings of being different from peers (D'Agostino & Edelstein, 2013). Symptoms of depression have been associated with feeling unattractive as a result of treatment-related scars in YAs with cancer (Olsson et al., 2018). While this relationship may be bidirectional, qualitative report by YAs suggests that significant observable changes may initiate distress, which perpetuates body image concerns (Brierley et al., 2019). Further, fear of cancer recurrence can contribute to behavioural changes, including avoidance (Simard et al., 2010) of emotionally evocative stimuli (Simard et al., 2010), which can perpetuate distress in the long term. Lastly, YAs who report poorer perceived social support are more vulnerable to higher levels of distress. Social support through online communities or community resources may help to reduce isolation (Coyne et al., 2016) and psychological adjustment to cancer (Haluska et al., 2002). Additional research is needed to clarify the direction of these relationships.

Limitations

Despite having a large, geographically diverse sample of YA cancer survivors, a number of limitations should be acknowledged. First, data from the YACPRIME study was collected five years after that of the matched non-cancer peers. Thus, variation in scores may reflect population differences in mental health; however, a Canadian population-based study demonstrated consistency in prevalence of mental health concerns over time (Chiu et al., 2020). Further, similar population discrepancies have been reported in other studies, with more mental health concerns reported by YA cancer survivors (Lang et al., 2018), and higher prevalence rates for moderate and severe distress within this population (Kaul et al., 2017). While it is possible that sociocultural factors may contribute to the population differences, they do not sufficiently explain the variance in these scores. Second, the YACPRIME and CCHS surveys used different enrolment strategies. Participants in the CCHS were systematically sampled whereas participants in the YACPRIME study were recruited. Consequently, participants within each sample may have different motivations for completing the survey; YA cancer survivors could have a stronger desire to convey difficulties leading to elevated scores. However, our findings are consistent with other comparative studies, which supports the presence of actual differences. Lastly, the sample in this study represents an older YA group which may limit the ability to compare these results to other studies with representation from those currently between 15-20. Individuals belonging to racial, ethnic, and gender minorities were also under-represented in our data, despite efforts to recruit diverse populations. This pattern continues to miss the detection of health outcome nuances specific to these demographic populations within oncology. Additionally, substantial discrepancies between male and female participants may also impact the generalizability of study findings. Research examining emotion expression proports that women tend to use more expressive language to describe their emotional responses (Goldshmidt & Weller, 2000), and demonstrate greater emotional expression (Chaplin, 2015). Alternatively, men are more likely than women to exhibit higher levels of alexithymia, the inability to identify or describe emotions (Levant et al., 2009), but demonstrate equal levels of physiological arousal to emotions (Chaplin, 2015), suggesting it is possible that the responses may not reflect the psychological or emotional experiences experienced by men and external validity of the presenting findings. Future research must listen to and prioritize research objectives reported by these particular patient groups to decrease barriers to participation in research and illuminate population specific needs to improve healthcare outcomes.

Clinical Implications

Being unemployed increases the risk of experiencing high distress for YA cancer survivors, and coupled with significant income discrepancies with matched peers, emphasizes the need for economic intervention. The development of formal screening measures and clinician-initiated conversations regarding patient financial concerns offer an opportunity for intervention regarding well-being for YA cancer survivors (Carrera et al., 2018). Additionally, support in engaging in part-time work or school may also assist individuals in making the transition to employment or education post-treatment (Gupta et al., 2016). Empirically supported treatments for body image dissatisfaction (Mehnert et al., 2011), and fear of cancer recurrence (van de Wal et al., 2018) have demonstrated the ability to reduce overall distress. Additionally, the importance of social support for YAs with cancer suggests effective interventions for this population should emphasize and foster connection between YAs with cancer (Richter et al., 2015). Addressing geographic, logistical, and institutional barriers to accessing these interventions is the necessary next step to reduce the distress discrepancies observed.

Conclusions

YA cancer survivors experience higher levels of distress compared to their peers, reflecting the disruptive developmental impact of a cancer diagnosis during young adulthood. Individuals belonging to this population who have less education, are not employed, are dissatisfied with their body image as a result of cancer, have poor social support, and report high levels of fear of cancer recurrence are increasingly vulnerable. These identified risk factors are modifiable and signify priority areas for additional supports, programming, and intervention.

Chapter 3: Prevalence and Factors Associated with Fear of Recurrence in a Mixed Sample of Young Adults with Cancer[2]

---

[2] **Chapter Reference for Publication:**

Lane, B. E., Garland, S. N., Chalifour, K., Eaton, G., Lebel, S., Galica, J., Maheu, C., Simard, S. (2019). Prevalence and factors associated with fear of recurrence in a mixed sample of young adults with cancer. *J Cancer Surviv, 13*(6), 842-851. doi:10.1007/s11764-019-00802-9

3.1 Abstract

PURPOSE: This study examined the prevalence of and factors associated with fear of cancer recurrence (FCR) in young adults (YAs).

METHODS: YAs diagnosed with cancer between the ages of 15-39 in Canada (n=461), who were currently 19 years or older, completed the Young Adults with Cancer in their Prime (YACPRIME) Study. The Fear of Cancer Recurrence Inventory Short Form (FCRI-SF) was the primary outcome. Scores $\geq$ 16 on the FCRI-SF indicate problematic levels and scores $\geq$ 22 represent clinically significant FCR. Covariates included demographic, clinical cancer variables, and co-morbid symptom measures. Univariate and multivariate logistic regression analyses were performed to identify variables associated with FCR.

RESULTS: Participants were predominantly female (88%) with a mean age of 32 years (*SD*=4.7). Problematic levels of FCR were present in 84% of YAs, and 59% met or exceeded the cutoff for clinically significant FCR. In the multivariate model, time since diagnosis of 5+ years was associated with a reduced likelihood of clinical FCR (Adjusted Odds Ratio [AOR]=0.354; p=.004), while having a previous recurrence was related to increased likelihood (AOR=3.468, p=.001). Other factors associated with clinical FCR in YAs with cancer were psychological distress (Mild: AOR=2.947, p=.003; Moderate: AOR=5.632, p<.0005; Severe: AOR=8.877, p<.0005), and cancer-related body image dissatisfaction (AOR=2.311, p=.004).

CONCLUSIONS: FCR is a pervasive problem for YAs diagnosed with cancer, with previous recurrence and psychological difficulties as factors associated with higher degree of fear.

IMPLICATIONS: Psychosocial interventions for YAs targeting depression and anxiety should also prioritize the treatment of FCR.

3.2 Introduction

Young adults (YAs) with cancer will spend the majority of their lives coping with cancer beyond the physical treatment of disease (Keegan et al., 2016). As per the National Cancer Institute (Adolescent and Young Adult Oncology Progress Review Group, 2006; Aubin et al., 2011), YAs encompass those aged 15 through 39 at diagnosis. YA cancer survivors experience impaired physical, emotional, cognitive, functional, and social quality of life up to 10 years post-diagnosis (Martens et al., 2014). There is often an expectation that life should return to 'normal' after treatment (Fitch et al., 2018), and patients are frequently unprepared for the long-term effects of cancer. Fear of cancer recurrence (FCR), defined as "fear, worry, or concern relating to the possibility that cancer will come back or progress" p. 3265 (Lebel et al., 2016), is one such unexpected long-term effect. FCR has been documented in various cancer types (Hanprasertpong et al., 2017; Petzel et al., 2012; Thewes et al., 2013; van de Wal et al., 2016), regardless of illness prognosis (Hedman et al., 2017), and has been shown to persist over time (Mehnert et al., 2013; Savard & Ivers, 2013).

Understanding the factors associated with FCR in YAs is a critical first step to developing appropriate services. Studies that have examined variables related to FCR in YAs have predominantly used sociodemographic and clinical cancer variables. Younger age is frequently associated with higher levels of FCR (Lebel, Tomei, et al., 2013; Mehnert et al., 2009; Shay et al., 2016; Simard et al., 2013; Thewes et al., 2013; van de Wal et al., 2016), but little research has examined whether the association between age and FCR differs within the YA age range of 15 to 39 years. Psychological distress has also been associated with higher levels of FCR (Simard et al., 2013). Distress is particularly relevant, considering that YAs with cancer report higher distress levels than their peers without cancer, with differences persisting into later adulthood (Jorngarden et al., 2007; Seitz et al., 2010). Further, higher levels of anxiety have been associated with FCR in breast and cervical cancer survivors (Hanprasertpong et al., 2017; Lebel, Beattie, et al., 2013), which are among the most common types of cancers diagnosed in YA women.

Beyond mental health, poor physical health, and increased severity of physical symptoms have been associated with greater FCR (Simard et al., 2013). Sleep disturbances are prevalent and persistent problems for cancer survivors (Ness et al., 2013), and poor sleep quality has been associated with higher FCR (Berrett-Abebe et al., 2015). Impaired body image as a result of cancer treatment is one of the most widespread negative impacts of cancer in young adulthood (Barnett et al., 2016; Bellizzi et al., 2012). YAs with cancer often feel or appear different than their peers (i.e., hair loss, scars, or changes in motor functioning), and these physical changes can increase distress and act as cancer reminders (D'Agostino & Edelstein, 2013; Epelman, 2013). Although these factors may be independently associated with higher levels of FCR, it is not yet known which, if any, contribute the most to FCR after adjusting for the impact of other significant factors.

In addition to factors that are associated with higher FCR, it is equally possible that there are protective factors that could serve to buffer against FCR. For example, the theory of post-traumatic growth suggests that it is possible to move forward from a cancer diagnosis and treatment in healthy ways (Zebrack et al., 2015). Strong interpersonal relationships (Bellizzi et al., 2012; Eom et al., 2013), could also serve as protective factors against experiencing high levels of FCR. However, no research has examined the relationships between FCR, post-traumatic growth, and social support in a YA sample, suggesting this is an essential area for further study.

Establishing the prevalence of FCR in YAs has been hampered by measurement issues (Simard et al., 2013). Within the YA cancer population, a systematic review of FCR has suggested the prevalence of FCR ranges between 31% and 85% (Yang et al., 2019). Using the Cancer Worry Scale, Thewes et al. found that in a sample of 73 YAs in the Netherlands, 62% experienced high levels of FCR (Thewes et al., 2018). Similarly, Sun and colleagues used the Fear of Progression Questionnaire-Short Form to measure FCR in a sample (n=249) of YAs in China. In their sample, 35.7% of patients reported dysfunctional levels of FCR (Sun et al., 2019). In the 2010 LIVESTRONG Survey, 85% of YAs with cancer (n=1,395) indicated yes on a single question about whether they worried about cancer coming back since completing treatment (Shay et al., 2016). While these results present preliminary information about the prevalence of FCR in YA cancer survivors, additional research is needed to clarify findings using a validated psychometric measure of FCR in a large, diverse sample of YAs.

The purpose of this current study was to document the prevalence and examine factors associated with FCR in a heterogeneous sample of YAs with cancer. Exploring these relationships can help to identify patients at an increased risk of FCR and inform treatment recommendations.

3.3 Methods

Participants

The current research uses data from the Young Adults with Cancer in their Prime

(YACPRIME) Study, the purpose of which was to provide a comprehensive picture of the needs of YAs with cancer in Canada. The YACPRIME study is a collaborative patient-oriented research project conducted in partnership with Young Adult Cancer Canada (YACC), the leading support and advocacy organization devoted to YAs living with, through, and beyond cancer. Patient partners played a crucial role in identifying FCR as a priority topic of exploration for the YA population, as well as choosing additional variables to study, recruiting participants, reviewing, and contextualizing findings. YACC helped to recruit participants through direct emails, media promotion, online advertisements, and social media posts. The study officially opened in June 2017 and closed March 2018 and received ethics approval from Memorial University's Interdisciplinary Committee on Ethics in Human Research (ICEHR). To be eligible to participate in the YACPRIME Study, YAs needed to have been diagnosed with cancer between the ages of 15-39, currently be 19 years of age or older to consent to participate and reside in Canada.

Six hundred and twenty-two individuals completed the YACPRIME study, however, for the present study, we restricted the sample to those currently between the age of 19 and 39 (n=508), with an additional 47 excluded that did not respond to the 9 items of the principal outcome measure, leaving a remaining sample size of 461. The mean age of the sample was 32.3 years (*SD* = 4.7). Participants were predominantly Caucasian (87%), female (87.6%), in committed relationships (67.5%), had between 14 and 18 years of education (58.6%), and 34.1% reported having personal incomes of less than $20,000. The most commonly reported cancer diagnoses/categories included blood cancers (27.1%), breast cancer (25.2%) and female genitourinary cancers (11.1%).

Approximately one-third of participants were diagnosed with Stage II cancer, with a median time since diagnosis of 3.0 years. Table 1 provides descriptive characteristics for the entire sample.

Table 1. *Sociodemographic variables.*

		Frequency (%)
		n = 461
Age, Mean (SD)		32.3 (4.7)
	< 26 Years	49 (10.6%)
	26 – 30 Years	98 (21.3%)
	31 – 35 Years	177 (38.4%)
	36 – 39 Years	137 (29.7%)
Age at Diagnosis		
	< 25 Years (Ref)	104 (22.6%)
	25 – 29 Years	127 (27.5%)
	30 – 33 Years	133 (28.9%)
	34 – 39 Years	94 (20.4%)
	Missing	3 (0.7%)
Sex		
	Male	57 (12.4%)
	Female	404 (87.6%)
Race/Ethnicity		
	White	401 (87.0%)
	Asian	17 (3.7%)
	Multi-racial/Ethnic Identity	16 (3.5%)
	Aboriginal/First Nations	13 (2.8%)
	Other	14 (3.0%)
Relationship Status		
	Single	150 (33.5%)
	In a relationship	311 (67.5%)
Children		
	No children	301 (65.3%)
	1+ children	160 (34.7%)
Education, Mean Years (SD)		17.0 (3.1)
	< 14 Years	45 (9.8%)
	14 – 18 Years	271 (58.6%)
	19+ Years	132 (28.6%)
	Missing	13 (2.8%)
Income		
	Less than $20,000	157 (34.1%)
	$20,000 to less than $40,000	107 (23.2%)

$40,000 to less than $60,000	91 (19.7%)
$60,000 or more	105 (22.8%)
Missing	1 (0.2%)
Cancer Diagnosis	
Breast	116 (25.2%)
Female Genitourinary	47 (11.1%)
Male Genitourinary	5 (1.3%)
Thyroid	30 (8.5%)
Blood Cancers	125 (27.1%)
Head & Neck	40 (8.7%)
Gastrointestinal	41 (8.9%)
Skin	15 (3.3%)
Multiple Types	23 (5.0%)
Other	5 (1.1%)
Cancer Stage	
Stage 1	62 (13.4%)
Stage 2	138 (29.9%)
Stage 3	106 (23.0%)
Stage 4	65 (14.1%)
Don't Know	59 (12.8%)
Not Applicable	31 (6.7%)
Previous Recurrence	
No	375 (81.3%)
Yes	86 (18.7%)
Time Since Diagnosis, Median Years (M, SD) Range 0-23 years	3.0 (3.8, 3.8)

Dependent Variable

Fear of cancer recurrence was measured with the Fear of Cancer Recurrence Inventory-Short Form (FCRI-SF) (Simard & Savard, 2015), which is comprised of nine items used to measure the severity of FCR. Participants answer questions regarding the degree to which they are anxious cancer will return, as well as the amount of time spent worrying about recurrence (Simard & Savard, 2009). The initial validation of the measure suggested a proposed cutoff of 13+ (Simard & Savard, 2015); however more recent examination suggests that scores of < 16 are suggestive of minimal levels of FCR, scores of 16-21 are suggestive of problematic levels of FCR, and scores of 22+ indicate clinically significant levels of FCR. These cutoff scores have demonstrated high sensitivity and adequate specificity (Fardell et al., 2018; Simard & Savard, 2015). Cronbach's alpha was 0.85, demonstrating high internal consistency within this sample.

Independent Variables

Sociodemographic variables and cancer history: Sociodemographic variables, cancer history data, and a single item regarding perceived connection to, and identification with, the YA cancer community were collected by self-report.

The Kessler Psychological Distress Scale (K10) was used to measure participants' distress within the last month and assesses symptoms of anxiety and depression (Kessler et al., 2002). The K10 consists of 10 items; scores across items are summed with a minimum score of 10 (indicating no distress) and a maximum score of 50 (indicating severe distress). Total scores ranging from 20-24 are suggestive of mild distress, scores from 25-29 are indicative of moderate distress, and scores ≥30 suggest severe distress (Andrews & Slade, 2001). The K10 has been successfully utilized with an adolescent and YA population (McCarthy et al., 2016). Cronbach's alpha was 0.90 within the sample.

The Short-Form Health Survey 12 (SF-12) Physical Component Summary (PCS) provided a measure of physical well-being and health-related quality-of-life and was used to complement mental health symptoms measured by the K10. Questions require participants to indicate functional limitations as a result of physical health in the last four weeks (Ware et al., 1996), and this measure has been used to assess physical functioning in adolescents and YAs with cancer (Wilder Smith et al., 2013). Participant responses are scaled to provide total scores ranging from 0-100, with a score of 50 indicating average health and a standard deviation of 10 (*User's manual for the SF-12v2 Health Survey*

2012). Scores ≥ 50 suggest good health, 40-49 as average health, 30-39 as poor health, and <30 as very poor health. Cronbach's alpha was 0.53 within the sample.

The Pittsburgh Sleep Quality Index (PSQI) was used to measure participants' self-reported sleep quality and potential sleep disturbances within the last month and includes 19 items with higher scores indicating worse sleep quality (Buysse, 1989). A total cutoff score of > 5 has been shown to have adequate sensitivity and specificity in determining sleep dysfunction (Buysse, 1989), with sufficient construct validity, and has been used in an adolescent and YA population (Beck et al., 2004; Daniel et al., 2016). Cronbach's alpha was 0.82 within the sample.

The Post Traumatic Growth Inventory (PTGI) was used to evaluate personal growth, change in perspective, and adaption, and has been used to measure growth within a cancer population (Cordova, 2001; Holtmaat et al., 2017; Jansen et al., 2011; Tedeschi, 1996). Scores on the PTGI were dichotomized to ease interpretation; total scores that had an average response of at least moderate (≥63) were categorized as moderate/high post-traumatic growth, with remaining total scores (≤62) classified as no/minimal post-traumatic growth (Jansen et al., 2011). Cronbach's alpha was 0.94 within the sample.

The Body Image Scale (BIS) was used to evaluate participants' body image dissatisfaction as a result of cancer and treatment, and are rated within the last week (Hopwood, 2001). There are no widely used clinical cutoffs for the BIS; however, Falk Dahl and colleagues used scores of ≥ 8 to signify higher body image dissatisfaction, and <8 to indicate lower body image dissatisfaction in women with breast cancer (Falk Dahl et al., 2010). Cronbach's alpha was 0.92 within the sample.

The Medical Outcome Study Social Support Survey (MOS-SSS) was used to measure participants' levels of perceived social support (Sherbourne & Stewart, 1991) and has been used in cancer and chronic illness populations (Priede et al., 2018). The mean total of social support reported by Sherbourne and Stewart was used as an average level of social support in a chronic illness population ($M = 70.1$), and the standard deviation ($SD = 24.2$) was used to categorize responses as below-average (low) social support (≤ 45.9) and above-average (high) social support (≥ 94.3) (Sherbourne & Stewart, 1991). Cronbach's alpha was 0.95 within the sample.

Statistical Analysis

Descriptive statistics were used to characterize the sample's demographic and clinical characteristics. Prevalence of clinical FCR was calculated using frequency data, comparing the proportion of participant scores that met or exceeded the cutoff of 22 in the total sample. The proportion of missing data was assessed to ensure the generalizability of the sample; the rate of missing data was low at 4.5% (Dong, 2013). Logistic regression uses complete case analysis and can provide asymptotically unbiased estimates under a wide range of missing-data assumptions (Bartlett et al., 2015). Univariate binomial logistic regression was used to examine associations between bio-psycho-social variables and clinical FCR (scores of ≥22 on the FCRI-SF (Fardell et al., 2018)) (Laerd Statistics, 2017). Covariates with p values <.10 were then simultaneously entered into a multiple binomial logistic regression model (Bursac et al., 2008). Nagelkerke R^2 was used to measure the amount of variance in FCR accounted for by the multivariate model (Nagelkerke, 1991). To evaluate the effectiveness of the predicted classification against the actual classification of clinical FCR in the multivariate model sensitivity, specificity, positive predictive value, and negative predictive value were used (Laerd Statistics, 2017). Analyses were conducted using SPSS Version 25. All tests were two-sided, with $p < 0.05$ indicating statistical significance.

3.4 Results

Approximately 84.4% of participants scored 16 or higher on the FCRI-SF, suggestive of maladaptive levels of FCR, with 59.2% of participants in the sample reporting scores equal to greater than 22, consistent with clinical levels of FCR. Using the initial proposed clinical cutoff of 13 or higher, 92.2% of the sample would meet or exceed this score. An examination of individual item responses indicated that participants reported the strongest endorsement for the item indicating it is reasonable to be worried about cancer, followed by being afraid that cancer will return, and thinking about recurrence triggering other unpleasant thoughts. Additionally, 16.2% (*n*=75) of participants reported spending a few or several hours a day preoccupied with thinking about the possibility of recurrence. Refer to Table 2 for complete descriptive data for the other psychological variables of interest.

Table 2. *Psychometric measures descriptives.*

	Measure Range	**Mean (SD)**	**Frequency %**
Fear of Cancer Recurrence Inventory – Short Form	0-36	22.8 (6.9)	
Kessler Psychological Distress Scale	10-50	25.1 (7.8)	
No distress (<20)			26.3%
Mild distress (20-24)			24.5%
Moderate distress (25-29)			20.8%
Severe distress (30+)			28.4%
SF12: Physical Component Summary	0-100	43.0 (9.5)	
Good (50+)			31.4%

Average (40-49)			31.7%
Poor (30-39)			29.6%
Very Poor (< 30)			7.3%
Pittsburg Sleep Quality Index	0-21	9.1 (3.9)	
Good Sleep (≤5)			19.0%
Poor Sleep (>5)			81.0%
Post Traumatic Growth Inventory	0-105	56.2 (22.1)	
Moderate/High PTG (63+)			41.4%
Minimal PTG (21-62)			58.5%
Body Image Scale	0-30	14.3 (8.6)	
Not dissatisfied (<8)			27.5%
Dissatisfied (8+)			72.5%
MOS-Social Support Survey	0-100	66.9 (21.6)	
High (94.3+)			10.4%
Average (45.9-<94.3)			71.9%
Poor (<45.9)			17.7%

Separate univariate binomial logistic regression models were used to identify significant independent factors associated with clinical FCR. For a complete list of demographic, medical, and psychometric variables, consult Table 3. At the univariate level, participants reporting five or more years since diagnosis were significantly less likely to experience clinical levels of FCR (Odds Ratio [OR] = 0.423 [0.263, 0.682], *p* = <.0005), when compared to participants with a diagnosis less than two years ago. Alternatively, having a previous recurrence meant participants were more likely to experience clinical levels of FCR (OR = 2.678 [1.561, 4.596], *p* <.0005). Several demographic factors were independently associated with higher levels of FCR, including older age at diagnosis, female sex, and having children. Level of distress was significantly associated with clinical FCR regardless of severity (Mild distress: OR = 2.292 [1.351, 3.891], *p* = .002, Moderate distress: OR = 5.452 [3.027, 9.818], *p* < .0005, Severe distress: OR = 7.449 [4.239, 13.092], *p* < .0005); as was poor sleep and body image dissatisfaction. Individuals who reported not feeling connected to the YA cancer community were significantly more likely to experience clinical FCR (OR = 1.623 [1.035, 2.546], *p* = .035). Variables not independently related to the likelihood of experiencing FCR included: current age, relationship status, years of education, income, cancer stage, physical health, post-traumatic growth, and social support.

A multivariate binomial logistic regression was conducted with all significant independent variables entered simultaneously. The logistic regression model was statistically significant, $\chi^2(14) = 116.427$, $p < .0005$, and these predictors explained 36.2% of the variance (Nagelkerke R^2) in clinical FCR. The multivariate model correctly classified 74.0% of cases; sensitivity was 83.3%, and specificity was 60.3%, while the positive predictive and negative predictive values were 75.5% and 71.1%, respectively. In the multivariate model, time since diagnosis of five or more years continued to be associated with lower levels of FCR (Adjusted Odds Ratio [AOR] = 0.354 [0.175, 0.781], *p* = .004). Individuals who identified previously experiencing a recurrence (AOR = 3.468 [1.630, 7.379], *p* = .001) were more likely to experience clinical FCR. Participants with mild, moderate, and severe psychological distress were more than 2.9 (AOR = 2.947 [1.457, 5.961], *p* = .003), 5.6 (AOR = 5.632 [2.365, 12.039], *p* = <.0005), and 8.9 (AOR = 8.977 [4.047, 19.472], *p* = <.0005) times more likely to experience clinical FCR than participants without distress. Experiencing body image dissatisfaction as a result of cancer (AOR = 2.311 [1.300, 4.107], *p* =.004) remained significantly related to an increased likelihood of clinical FCR. At the multivariate level, after adjusting for covariates, age at diagnosis, parental status, sleep disturbance, and connection to the YA cancer community were no longer significantly associated with FCR.

Table 3. *Factors associated with clinical levels of FCR.*

	Univariate Logistic Regression Analysis		Multivariate Logistic Regression Analysis	
	Odds Ratio [95%CI]	*P*	Adjusted Odds Ratio [95%CI]	*P*
				<.0005*
Age		.183†		
< 26 Years (Ref)	1			
26 – 30 Years	0.716 [0.356, 1.439]	.348		
31 – 35 Years	1.175 [0.612, 2.256]	.629		
36 – 39 Years	0.789 [0.405, 1.536]	.486		
Age of diagnosis		**.012†**		
< 25 Years (Ref)	1		1	
25 – 29 Years	1.414 [0.840, 2.380]	.192	0.807 [0.391, 1.669]	.563
30 – 33 Years	2.340 [1.376, 3.978]	**.002**	1.272 [0.557, 2.904]	.568
34 – 39 Years	1.821 [1.031, 3.213]	**.039**	0.998 [0.410, 2.427]	.997
Sex				
Male (Ref)	1		1	
Female	2.400 [1.363, 4.226]	**.002**	2.172 [0.995, 4.739]	.051
Relationship status				
Single (Ref)	1			
In a relationship	1.169 [0.787, 1.735]	.439		
Children				
No children (Ref)	1		1	
1+ children	1.511 [1.015, 2.250]	**.042**	1.313 [0.741, 2.326]	.351
Education		.529†		
< 14 years (Ref)	1			

14 – 18 years	0.820 [0.425, 1.582]	.554		
19+ years	0.704 [0.349, 1.418]	.326		
Income		.272†		
< $20,000 (Ref)	1			
$20,000 to < $40,000	0.669 [0.404, 1.108]	.119		
$40,000 to < $60,000	0.668 [0.394, 1.134]	.136		
$60,000 or more	0.672 [0.405, 1.116]	.125		
Cancer Stage		.364†		
Stage 1 (Ref)	1			
Stage 2	0.856 [0.459, 1.594]	.728		
Stage 3	0.908 [0.473, 1.742]	.604		
Stage 4	0.727 [0.355, 1.486]	.155		
Don't Know	0.698 [0.336, 1.450]	.292		
Not Applicable	0.397 [0.164, 0.960]	.051		
Time Since Diagnosis		**<.0005†**		
< 2 years (Ref)	1		1	
2 – 4 years	1.163 [0.733, 1.847]	.521	1.448 [0.788, 2.661]	.233
5+ years	0.423 [0.263, 0.682]	**<.0005**	0.354 [0.175, 0.781]	**.004**
Previous Recurrence				
No (Ref)	1		1	
Yes	2.678 [1.561, 4.596]	**<.0005**	3.468 [1.630, 7.379]	**.001**
Psychological Distress (K10)		**<.0005†**		
No distress (<20) (Ref)	1		1	
Mild distress (20-24)	2.292 [1.351, 3.891]	**.002**	2.947 [1.457, 5.961]	**.003**
Moderate distress (25-29)	5.452 [3.027, 9.818]	**< .0005**	5.632 [2.365, 12.039]	**<.0005**
Severe distress (30+)	7.449 [4.239, 13.092]	**< .0005**	8.877 [4.047, 19.472]	**<.0005**
Physical Component Summary (SF-12 - PCS)		.810†		
Good (50+) (Ref)	1			
Average (40-49)	1.083 [-0.655, 1.789]	.757		
Poor (30-39)	1.284 [0.766, 2.151]	.343		

Very Poor (< 30)	1.043 [0.459, 2.367]	.920		
Pittsburgh Sleep Quality Index (PSQI)				
Good Sleep (≤5) (Ref)	1		1	
Poor Sleep (>5)	1.786 [1.104, 2.890]	**.018†**	0.730 [0.367, 1.450]	.368
Post Traumatic Growth (PTGI)				
Moderate/High PTG (63+) (Ref)	1			
Minimal PTG (21-62)	0.976 [0.669, 1.424]	.901		
Body Image Dissatisfaction (BIS)				
Not dissatisfied (<8) (Ref)	1		1	
Dissatisfied (8+)	4.180 [2.684, 6.510]	**<.0005**	2.311 [1.300, 4.107]	**.004**
Social Support (MOS-SSS)		.224†		
High (94.3+) (Ref)	1			
Average (45.9-<94.3)	1.225 [0.654, 2.294]	.526		
Poor (<45.9)	1.820 [0.855, 3.874]	.120		
Connection to YA Cancer Community				
Connected (Ref)	1		1	
Not connected	1.623 [1.035, 2.546]	**.035**	1.454 [0.814, 2.599]	.206

† Overall significance for variables with more than two categories at the univariate level.

* Significance for the overall multivariate model.

Continuous variables were categorized based on available data, or population distribution within the sample.

3.5 Discussion

The goal of the present study was to determine the prevalence of, and factors associated with, FCR in a diverse sample of YA cancer survivors. We found that 84% of our sample of 461 YAs with cancer experienced problematic levels of FCR (score ≥ 16) and 59% met or exceeded the cutoff of 22 to identify clinically significant levels of FCR (Fardell et al., 2018). Using the initial cutoff of 13 or more proposed in the validation of the measure (Simard & Savard, 2015), 92% of the sample would be considered to have evidence of FCR. The most appropriate clinical cutoffs for the YA age group have not been determined; however, the level of clinically significant FCR in our study falls within the range of prevalence rates previously reported in the literature, both in the general cancer population (Simard et al., 2013) and in YAs particularly (Thewes et al., 2018).

Demographic and Clinical Correlates of FCR in YA cancer survivors

Current age within the YA sample was not significantly related to higher levels of FCR, nor was the age at which cancer was diagnosed. This important finding suggests that FCR impacts YAs across this age range as opposed to younger age more generally. Cancer stage was not a significant predictor of clinical FCR in our study, which suggests that fear is not directly related to prognosis and might be more of a subjective assessment of the impact of cancer (Crist & Grunfeld, 2013; Hedman et al., 2017; Koch et al., 2013; Savard & Ivers, 2013). Similarly, poorer physical health was not a significant predictor of experiencing clinical FCR.

Participants who were more than five years out from their cancer diagnosis were significantly less likely to experience clinical FCR than participants who reported having cancer for less than two years. The 5-year relative survival rate is a standard metric for measuring illness prognosis and response to treatment (*Understanding Statistics Used to Guide Prognosis and Evaluate Treatment*, 2016). Increased cancer duration may provide patients with greater exposure to cancer-related knowledge and expertise, which helps to reduce FCR over time (Lichtenthal et al., 2017). Alternatively, having experienced a cancer recurrence was associated with 3.5 times the likelihood of experiencing FCR. Individuals who have had a recurrence may be more likely to perceive symptoms, physical changes or health information, as a greater threat to their health and well-being and consequently experience higher FCR (Fardell et al., 2016; Rippetoe, 1987).

Psychological Correlates of FCR in YA cancer survivors

Participants who reported any degree of psychological distress were more likely to experience clinical FCR than individuals without distress. Anxiety has been reported to mediate the relationship between age and FCR (Lebel, Beattie, et al., 2013), and there is evidence supporting the interaction between FCR and pathological cognitive processes, like rumination (Liu et al., 2018), which is apparent in anxiety and depressive disorders (Nolen-Hoeksema, 2000). These underlying factors hint at the relationship between these constructs; however, the direction and nature of the relationship between pre-existing depression and anxiety symptoms with FCR requires further exploration. The present study is the first to demonstrate an association of body image dissatisfaction with FCR. Participants with greater body image dissatisfaction were 2.5 times more likely to experience clinical FCR than participants with less body image dissatisfaction. Physical changes to body image can serve as reminders of the substantial impact that treatment has had on the individual (D'Agostino & Edelstein, 2013), and possibly compound fears surrounding recurrence. Sleep disturbance, levels of post-traumatic growth, social support, and feelings of connection to other YAs with cancer were not related to FCR.

Implications for Treatment of FCR in YA cancer survivors

Our findings support past research suggesting that patients are more likely to experience elevated levels of FCR in the early stages of diagnosis and treatment (Humphris, 2003; Savard & Ivers, 2013) and after experiencing a recurrence. Clinicians working with YAs with cancer should consider providing interventions during the early phases of treatment and after subsequent health challenges to address the impact of FCR more effectively. Exposure therapies could be used to help patients manage fear in response to emotionally evocative stimuli (Simonelli et al., 2017), and the cognitive features of FCR indicate YAs may benefit from cognitive behavioural therapy (CBT) and acceptance-based approaches (Mutsaers et al., 2016). Our findings suggest that incorporating body image content into FCR interventions and focusing on those individuals who have experienced a recurrence already may allow for personalized treatment by targeting concerns that may contribute to their fears.

Limitations

The study utilized a cross-sectional design, which does not allow us to determine the direction of the observed associations. Men and racial and ethnic minorities were under-represented, which impacts the generalizability of our findings to the larger YA population. Lastly, medical information was collected using self-report, and data has the potential to reflect inaccuracies.

Conclusions

The majority of YAs diagnosed with cancer experience clinically significant levels of FCR. The findings of this study can be used to refine the identification of individuals who are at risk of experiencing severe levels of FCR: including YAs with a more recent cancer diagnosis, those who have experienced recurrence, those with body-image dissatisfaction, and those with higher levels of psychological distress. By targeting and tailoring interventions, healthcare providers will be better equipped to meet the different needs of the YA population.

Chapter 4: Final Discussion

4.1 Summary of Main Findings

This body of work utilized national, cross-sectional data to examine the psychological consequences of cancer for YAs in Canada. The first study investigated cancer's contribution to the psychological distress of YAs by comparing them to age, sex, and education matched peers. YAs with cancer, on average, reported moderate levels of distress, significantly greater than the subclinical levels reported by matched peers. These findings are consistent with other studies that have used healthy comparison samples. Compared to matched peers, YAs with cancer reported poorer perceived health quality and were more likely to report being in a relationship, be unattached and living with others, living with parents, and have an annual income of less than $40,000. This study also identified that not working, body image dissatisfaction, poor social support, and maladaptive and clinical levels of FCR were associated with high distress in YAs with cancer. YAs with cancer were more likely to report impaired mental and physical health, and be finically disadvantaged, illustrating increased vulnerability for impaired global well-being than other individuals experiencing comparable developmental stressors. Additionally, diverse factors, including financial, social and emotional resources, enhance YAs with cancer’s risk and require holistic psychosocial support to assist them with coping with the long-term impacts of cancer.

The second study in this investigation examined the prevalence of, and factors associated with, FCR using the same sample of YA cancer survivors described above. Maladaptive FCR was reported by 84% of YAs with cancer in the sample, and 59% met or exceeded the cutoff for clinically significant FCR. Having a cancer recurrence, mild, moderate and severe levels of psychological distress and body image dissatisfaction were associated with an increased likelihood of experiencing clinical levels of FCR. Having a time since diagnosis of five years or more was associated with a decreased likelihood of experiencing clinical FCR. Clinical levels of FCR represent an ubiquitous psychological challenge for YAs with cancer and early identification in patients with a recurrence history, distress, or impaired body image can assist with pinpointing patients who may benefit from psychological interventions.

4.2 Implications

There is a global acceptance that cancer impacts a patient's mental and physical health, requiring psychosocial care alongside physical cancer treatment. The studies outlined in this investigation provide essential contributions to our collective understanding of psychological health and well-being for YAs with cancer, increasing our ability to identify particularly vulnerable individuals. This section will review a growing body of literature examining psychosocial interventions to provide possible solutions to address the specific needs of YAs with cancer in Canada.

A meta-analysis and systematic review conducted by Richter et al. examined the impact of psychosocial interventions on the mental health of YAs compared to control participants on domains of well-being, cancer knowledge and psychological distress (Richter et al., 2015). Twelve studies met inclusion criteria that contained interventions facilitated with technology, psychoeducation, physical exercise, or that combined several elements, including peer support, individual work with a healthcare practitioner, and elements of the other intervention types. The review revealed some enhanced outcomes for patients compared to control participants and subjective improvements; however, when results across studies were pooled, improvements for participants receiving interventions disappeared, suggesting significant limitations in current psychosocial services. Moreover, Walker and colleagues reviewed psychosocial interventions for patients diagnosed in early young adulthood and found that nine of the 11 included studies yielded benefits across diverse well-being outcomes (Walker et al., 2016). The limited studies which included YAs found improvements in measures of anxiety and quality-of-life for YAs not receiving treatment, but no difference in YAs currently undergoing treatment. Osborn and colleagues reported short-term and long-term benefits of CBT for anxiety, depression and quality-of-life for adult cancer survivors (Osborn et al., 2006). Together these conflicting studies suggest that to be more effective, YAs may require interventions tailored to their needs, reflecting the intersection of their cancer care and developmental requirements.

To better understand the intervention preferences of YAs, Rabin and colleagues interviewed 20 YA patients individually, having them assess the helpfulness of varied intervention types and their delivery preferences (Rabin et al., 2013). Participants reported that effective and helpful interventions needed to accommodate the demands associated with their various academic, professional and social roles, noting it can add pressure to incorporate behavioural interventions into their busy lives. One YA participant noted that flexibility in attendance and less frequent scheduling would address these competing needs. A similar need for balance was identified in the value of in-person interventions and carving out the time needed to attend them. The convenience of intervention delivery was also a key theme identified by participants, and many suggested that web-based or remote services would increase patients' ability to engage in services. Finally, social support, either available through online platforms and social media, or connecting with others, was identified as an essential component for YAs. In the present investigation, poor social support increased the likelihood of experiencing high distress, suggesting a desire for social support may be an attempt to address psychological responses to cancer.

An integrative review conducted by Thorton et al. examined studies (n=17) of psychosocial interventions for YAs with cancer to determine thematic elements associated with successful intervention outcomes for this population (Thornton et al., 2020). Similarly, engaging with technology in interventions and peer support were reported as essential themes for effective YA interventions. Utilizing creative expression, accessing individual support, encouraging participants to engage in physical activity and developing relationships and establishing supportive communication with clinicians were also identified as characteristics helping tailor interventions for YAs with cancer. YAs are rarely represented as a unique population in intervention research. Understanding the qualities that increase the success and application of theoretical research for YAs with cancer is crucial for adapting existing interventions to reflect this population's competing needs.

Psychoeducational interventions that provide patients with disease-specific information to assist them in addressing treatment-related concerns have successfully addressed mental health symptoms, fostering resilience and building self-efficacy (Dastan & Buzlu, 2012; Matsuda et al., 2014; Wu et al., 2018). Addressing YAs' preference for timely interventions, researchers have begun exploring delivering psychoeducational interventions using smartphones for addressing FCR (Akechi et al., 2018) and web-based self-help to manage fertility-related distress (Lampic et al., 2019). These studies offer promising intervention designs providing convenient and tailored ways for YAs to manage distress and FCR.

To address overall health-related quality-of-life, Aubin et al. created a CBT intervention designed for YAs with cancer (Aubin et al., 2019). Participants (n=119) were randomly assigned to receive the three-session interventions delivered in-person or over Skype, based on individual choice, or the control condition. Participants were assessed at baseline, post-intervention three-month follow-up. Only participants completing the intervention condition reported significant improvements in mental health symptoms, emotional well-being and quality-of-life. Further, there were no significant differences in YA outcomes between participants receiving face-to-face or Skype intervention delivery. The brief design of this intervention helps address YA patient's preference for convenience and may be particularly beneficial for individuals who cannot commit to longer-term interventions. This design also offers individual support, a characteristic of successful past YA interventions. Giving participants the ability to select their intervention format may also account for positive outcomes and the lack of significant outcome differences for participants completing the intervention. Consequently, the opportunity to customize services may enhance outcomes for YA patients, and the impact of increased intervention choice warrants further exploration.

Mindfulness-based interventions have also been explored to address mental health symptoms and quality of life for YAs with cancer in Canada. Nissim and colleagues developed a mindfulness-based cognitive group therapy for YAs with varied cancer diagnoses (Nissim et al., 2020). Seventy-seven YAs participated in an eight-week program, including meditation, yoga, experiential practices, psychoeducation, group support and completed a battery of psychometric measures assessing anxiety, depression, quality-of-life, stress and compassion. The intervention was deemed acceptable to participants based on engagement and attendance, and significant benefits were reported across assessment measures. A small portion of participants completed follow-up interviews and noted additional benefits of increased ability to accept their emotions, build a sense of belonging, address body dissatisfaction and FCR. Multifaceted mindfulness-based interventions offer promising outcomes for addressing mental health symptoms generally and FCR and body image concerns, which the current investigation has highlighted as an essential risk factor for global distress and clinical levels of FCR.

A comparable study conducted by van de Gucht and colleagues developed a mindfulness-based intervention for YAs (n=16) post-cancer treatment (Van der Gucht et al., 2017). Participants were assessed twice before the intervention, after completing the eight-week group and at a three-month follow-up on measures assessing the quality-of-life and emotional distress. Participants demonstrated significant increases in quality-of-life and decreases in emotional distress between baseline and post-intervention and three-month follow-up. Changes in FCR was not independently noted; however, FCR was significantly negatively correlated to quality-of-life, providing further evidence that FCR may be treated with mindfulness interventions. Additionally, both mindfulness programs were offered in a group format, catering to YAs preference for interventions with social support and accountability (Rabin et al., 2013), illustrating promise for their ability to address the unique psychosocial needs of YAs with cancer.

Existing research has seldom examined interventions specifically designed to target psychological distress. Seciniti et al. conducted a meta-analysis to explore the relationship between cancer acceptance and psychological distress in adults with cancer (Secinti et al., 2019). Using pooled data from 78 studies, authors examined the relationships between cancer acceptance and general distress, cancer-specific distress, depression and anxiety symptoms; significant, negative effect sizes were found for all relationships. These findings illustrate the possible benefits of increasing cancer acceptance on reducing distress, suggesting that therapeutic modalities like Acceptance and Commitment Therapy (ACT) (Ost, 2014) could directly address global, psychological distress and cancer-specific distress. Exploring how cancer acceptance could address the high prevalence rates of distress among YAs with cancer represents an important future research area. Researchers have begun to develop ACT-based programs and protocols for adolescents and YAs with cancer; initial findings revealed three-day ACT group program to be both feasible and acceptable based on patient feedback, further illustrating the possible gains for this population(Clarke et al., 2020).

There has been growing interest in the development of interventions created to address FCR specifically. In a systematic review and meta-analysis, Taube et al. examined the effect of psychological interventions on FCR in adults with cancer (Tauber et al., 2019). Thirty-two randomized controlled trials and open trials were included in the analyses, and overall there was a significant small effect of psychological interventions in addressing FCR post-intervention and maintained for analyses measuring later follow-up. Interventions that focused on cognitive processes (i.e., worry, rumination) instead of the content of thoughts yielded significantly larger effect sizes than interventions using traditional CBT. Greater benefits were also noted for group-based interventions compared to individually administered interventions. Sharpe and colleagues sought to examine mediating and moderating factors that improved outcomes in a specialized intervention, ConquerFear, created with ACT principles to treat clinical FCR (Sharpe et al., 2019). Participants (n=150) completed the five-session program and were assessed at three time points; pre- and post-intervention, and at a six-month follow-up. Participants with the highest initial levels of clinical FCR showed greater improvements than participants in the relaxation, control group intervention. Mediation analysis revealed that changes in assessments of worry and intrusive thoughts partially mediated the relationship between treatment condition and FCR. These studies collectively provide compelling evidence for the use of psychological interventions that provide patients with ways to cope or change their engagement with thinking patterns that can address FCR. However, both studies utilized diverse adult samples, limiting the ability to draw conclusions for YAs with cancer.

4.3 Strengths

The population examination facilitated by both studies utilized a national dataset to capture the diverse experiences of YAs with cancer beyond provincial healthcare differences. Within the YA population in the United States, Kaul and colleagues are among the first to compare psychological distress differences, specifically between YAs with cancer and their non-cancer peers, using a large, representative national sample (Kaul et al., 2017). Young adults in North America share some cultural similarities; however, national differences in healthcare pose significant challenges in comparing health outcomes across countries (Lau et al., 2014).

There has been limited Canadian research on distress in YAs with cancer. Lang and colleagues used data from the Canadian Community Health Survey to compare perceived health and prevalence of mental illness between YA cancer survivors, YAs without cancer, older adult cancer survivors, and older adults without cancer (Lang et al., 2018). Respondents provided an overall measure of self-perceived health and mental health on Likert scales, ranging from excellent to poor and yes/no responses to a healthcare professional diagnosed with a mood or anxiety disorder. Unfortunately, this study was limited by estimating the prevalence of mental health concerns using previous mental health diagnoses and perceived mental health with a single item. The first study expands on YA findings illustrated by Lang et al.(2018) by using a validated measure to assess mental health symptoms within the last month (Andrews & Slade, 2001), as opposed to an estimate of the prevalence of mental health concerns by measuring previous mental health diagnoses and perceived mental health with a single-item. Using the K10 reduces the likelihood of having participants report past mental health diagnoses that do not necessarily provide a clear indication of current mental health functioning.

The second study provides the first estimate of FCR within a Canadian sample (Yang et al., 2017). The use of the FCRI-SF provides a reliable measurement of FCR within this population, where many existing studies have utilized single-item or study-specific questions (Yang et al., 2017). In addition to the studies' nuanced findings in this investigation, this is the first study to examine the relationship between body image and FCR. Body image is integral in self-esteem and identity for YAs generally (Tiggemann, 2004), and YAs with cancer often have body image concerns as a result of cancer (Barnett et al., 2016; Bellizzi et al., 2012), which can have clinical, psychosocial implications for survivors (Zucchetti et al., 2017). This study provides important theoretical support for this relationship, necessary to effectively identify YAs with clinical FCR as well as provide insights into possible contributing factors for individuals in this population.

Another strength of the studies is the inclusion of YAs survivors with diverse cancer diagnoses. Studies that have previously examined psychological distress and FCR within YAs with cancer have utilized narrow samples, mainly focusing on precise diagnoses (Hall et al., 2016; Kim et al., 2017; Naik et al., 2020), or excluding participants based on clinical characteristics (Kaul et al., 2017; Lang et al., 2015; Lang et al., 2018). Given the significant stressors and mental health vulnerabilities shared across the YA cancer population, it is much more meaningful to include YAs across different diagnoses than older survivors of the same diagnosis (Naik et al., 2020; Shay et al., 2016; Smrke et al., 2020).

Finally, utilizing a POR approach, wherein YAs with cancer determined the studies' objectives and participated in the dissemination of findings, ensures the results will be communicated in a way that is relevant and important to the wider patient population. Creating POR has also enhanced the translation of findings, by supporting the individuals directly involved in the projects with communicating results to wider patient networks to ensure clear messaging and decreasing the time taken for patients to access information.

4.4 Challenges and Limitations

The data collected by the YACPRIME study reflected national population distribution (Statistics Canada, 2020), but the most significant limitations of the studies included in this investigation relate to challenges associated with capturing the diverse demographic features of YAs with cancer in Canada. Participants were predominantly female sex, despite substantial effort dedicated to enhancing male participants' recruitment through targeted digital advertisements, snowball recruitment through male survivors, and including male survivors in promotional material. Similar recruitment rates of male participants have been demonstrated in health research (Maher et al., 2014), illustrating further investigation is needed to address this limitation more broadly (Ryan et al., 2019). Existing research reports sex differences in psychological distress (Burgoyne et al., 2015; Koyama et al., 2016; Wang et al., 2014) and FCR (Shay et al., 2016; Simard et al., 2013; Wang et al., 2015) for YAs with cancer; however, we did not find significant differences between female and male scores for total distress or FCR. Regardless, male participants' limited representation may not represent the true diversity in psychological responses to cancer.

Representation from diverse races, ethnicities, and genders was also limited, as only roughly 12% of participants in each study identified as non-White. Matching participants on age, sex and education required excluding an additional nine participants as there were not enough comparable non-cancer peers; therefore, with limited participant diversity we did not use race or ethnicity as a fourth matching variable. Black, Indigenous, and people of colour experience a greater relative risk of being diagnosed with cancer (Mazereeuw et al., 2018; Moore et al., 2015). However, research has illustrated that participants with varied racial and ethnic identities do not have the same health outcome as white patients with cancer (Dixon et al., 2019; Esnaola & Ford, 2012). For example, Canadian census data for Indigenous and non-Indigenous Canadians found that indigenous patients reported lower five-year survival than matched peers, consistent across 14 of the most common diagnoses (Withrow et al., 2017). In the United States, Black patients were less likely to receive chemotherapy to treat pancreatic cancer than white patients (Wright et al., 2020). Outcome differences are due to systemic healthcare barriers to accessing treatment that non-white patients with cancer face (Esnaola & Ford, 2012; Horrill et al., 2019). Inability to effectively capture the needs of YAs with cancer of varied ethnicities and races further compounds the inequality of adequate supports. Participants within this sample were also older, with a mean age of 32 across both studies. YAs share the same developmental concerns, but how these manifest by age groups within this population may be very different. For example, younger YAs may be increasingly concerned about educational training and establishing their careers, while older YAs may be concerned with disruptions and maintaining their careers. Different reactions to stressors across this population limits the discussion of age-related nuances for YAs.

Elements of the studies' methodology also limited this investigation. The data collection was cross-sectional, restricting the ability to infer the direction of relationships observed and the stability of these associations over time. Another methodological limitation was that these studies also relied on self-report data for cancer history and psychosocial variables. Self-report data can be prone to many individual biases and may increase the risk of inaccurate measurement of variables due to limited accuracy in recall, impaired self-awareness, and motivation when completing measures (Rosenman et al., 2011); however, a study by Short and colleagues found participants self-report was comparable to administrative records for health utilization data (Short et al., 2009). This provides reassurance that estimates included in the study are likely to reflect accurate health and symptom data.

The methodology of this study was also limited by the use of convenience sampling for YAs with cancer. Critique of convenience sampling emphasizes that this sampling strategy has inherent bias and fails to represent the actual characteristics of the population of the study. Within the investigation, this strategy may have contributed to the unequal representation of males and diverse patient groups. The possibility of inaccurately presenting the population's concerns is a particular limitation for Study 1, which compares the convenience sampling data for YAs with cancer to the systematically sampled data for non-cancer peers. Different sample strategies may have compounded the substantial population differences in distress reported by the study. However, research comparing outcomes across conveniently sampled and probability sampled participants with diabetes reported comparable results across samples (Bujang et al., 2012), suggesting that this strategy is still acceptable for estimating a population's experiences. Therefore, this limitation does not likely account for the significant discrepancies between this study's samples, supporting meaningful clinical population differences.

Additionally, it is unlikely this difference in scores could also be compounded by the five-year discrepancy in data collection between the CCHS and YACPRIME samples. National consistency in prevalence of Canadian mental health concerns over this period (Chiu et al., 2020) and similar discrepancies in peer comparison research with data collected in the same period (Lang et al., 2018) further support our findings.

4.5 Future Directions

To acknowledge limitations of the present studies and the existing body of literature, several future directions for research are suggested. POR’s ability to enhance the quality and applicability of findings offers important benefits for future research for YAs with cancer. Including patients as future investigators for psychosocial programs would likely address the mixed findings regarding intervention effectiveness, and the consensus regarding tailoring program content and delivery to meet YA specific needs. POR has the added benefit of supported KT of research findings by supporting patient partners in sharing findings within larger patient networks.

Participants endorsement of worry and preoccupation associated with distress and FCR represents important cognitive targets for effective interventions for YAs. These concerns are consistent with cognitive behavioural conceptualization of cancer-related concerns for YAs (Hagstrom et al., 2020). Consequently, future studies exploring the provision of third-wave cognitive behavioural interventions that support acceptance and distress tolerance would offer important clinical insights in improving psychological outcomes for YAs with cancer. Based on investigation outcomes, and YA preference for interventions it would also be beneficial to further explore the nuances of social support's impact on distress, examining outcome improvements for services that are provided in individual and group-based formats.

Across both studies, body image dissatisfaction was the only consistent significant predictor of high distress and clinical FCR. Exploration of the relationships between these variables would further clarify psychological health concerns for patients and assist with developing psychosocial treatment goals for YAs with cancer.

4.6 Conclusions

This investigation provides important insights into the prevalence of distress and FCR for YAs with cancer in Canada. Young adulthood represents a difficult developmental period and increased likelihood of experiencing mental health symptoms; compared to peers matched on age, sex, and education, YAs with cancer had significantly greater psychological distress. Greater years of education were associated with decreased distress, while not being employed, body image satisfaction, poor social support and elevated FCR were associated with an increased likelihood of distress. Being diagnosed with cancer five or more years ago was associated with a decreased likelihood of clinical FCR. Having a previous recurrence, clinical levels of psychological distress and body image dissatisfaction were associated with an increased likelihood of clinical FCR. Psychological distress and FCR represent important psychological side effects for YAs, and efforts to determine the relationship between these variables are essential for future psychosocial care for this population.

Given the high prevalence rates of psychological responses to cancer for this population, health practitioners must prioritize identifying vulnerable YAs. To adequately address the substantial psychosocial support needs of YAs with cancer, it is necessary to create or tailor existing programming to account for competing pressures experienced by YAs.

References

Abbey, G., Thompson, S. B., Hickish, T., & Heathcote, D. (2015, Apr). A meta-analysis of prevalence rates and moderating factors for cancer-related post-traumatic stress disorder. *Psychooncology, 24*(4), 371-381. https://doi.org/10.1002/pon.3654

Adolescent and Young Adult Oncology Progress Review Group. (2006). *Closing the gap: Research and cancer care imperatives for adolescents and young adults with cancer*. https://www.livestrong.org/content/closing-gap-research-and-care-imperatives-adolescents-and-young-adults-cancer

Akechi, T., Yamaguchi, T., Uchida, M., Imai, F., Momino, K., Katsuki, F., Sakurai, N., Miyaji, T., Horikoshi, M., Furukawa, T. A., Iwata, H., & Uchitomi, Y. (2018, Nov 8). Smartphone problem-solving and behavioural activation therapy to reduce fear of recurrence among patients with breast cancer (SMartphone Intervention to LEssen fear of cancer recurrence: SMILE project): protocol for a randomised controlled trial. *BMJ Open, 8*(11), e024794. https://doi.org/10.1136/bmjopen-2018-024794

American Cancer Society. (2020). *Types of cancer that develop in young adults*. Retrieved September 11, 2020 from https://www.cancer.org/cancer/cancer-in-young-adults/cancers-in-young-adults.html

Ander, M., Gronqvist, H., Cernvall, M., Engvall, G., Hedstrom, M., Ljungman, G., Lyhagen, J., Mattsson, E., & von Essen, L. (2016, May). Development of health-related quality of life and symptoms of anxiety and depression among persons diagnosed with cancer during adolescence: a 10-year follow-up study. *Psychooncology, 25*(5), 582-589. https://doi.org/10.1002/pon.3965

Andrews, G., & Slade, T. (2001). Interpreting scores on the kessler psychological distress Scale (K10). *AUST NZ J PUBL HEAL, 25*(6), 494-497.

Aubin, S., Barr, R., Rogers, P., Schacter, B., Bielack, S. S., Ferrari, A., Manchester, R. A., McMaster, K., Morgan, S., Patterson, M., & Perrilli, A. S. (2011). What should the age range by for AYA oncology. *J Adolesc Young Adult Oncol, 1*, 3-10. https://doi.org/https://doi.org/10.1089/jayao.2011.1505

Aubin, S., Rosberger, Z., Hafez, N., Noory, M. R., Perez, S., Lehmann, S., Batist, G., & Kavan, P. (2019, Apr). Cancer!? I Don't Have Time for That: Impact of a Psychosocial Intervention for Young Adults with Cancer. *J Adolesc Young Adult Oncol, 8*(2), 172-189. https://doi.org/10.1089/jayao.2017.0101

Bandelow, B., & Michaelis, S. (2015). Epidemiology of anxiety disorders in the 21st century. *Dialogues Clin Neurosci, 17*, 327-335.

Barnett, M., McDonnell, G., DeRosa, A., Schuler, T., Philip, E., Peterson, L., Touza, K., Jhanwar, S., Atkinson, T. M., & Ford, J. S. (2016, Oct). Psychosocial outcomes and interventions among cancer survivors diagnosed during adolescence and young adulthood (AYA): a systematic review. *J Cancer Surviv, 10*(5), 814-831. https://doi.org/10.1007/s11764-016-0527-6

Bartlett, J. W., Harel, O., & Carpenter, J. R. (2015, Oct 15). Asymptotically Unbiased Estimation of Exposure Odds Ratios in Complete Records Logistic Regression. *Am J Epidemiol, 182*(8), 730-736. https://doi.org/10.1093/aje/kwv114

Beck, S. L., Schwartz, A. L., Towsley, G., Dudley, W., & Barsevick, A. (2004, Feb). Psychometric evaluation of the Pittsburgh Sleep Quality Index in cancer patients. *J Pain Symptom Manage, 27*(2), 140-148. https://doi.org/10.1016/j.jpainsymman.2003.12.002

Bellizzi, K. M., Smith, A., Schmidt, S., Keegan, T. H., Zebrack, B., Lynch, C. F., Deapen, D., Shnorhavorian, M., Tompkins, B. J., Simon, M., Adolescent, Young Adult Health, O., & Patient Experience Study Collaborative, G. (2012, Oct 15). Positive and negative psychosocial impact of being diagnosed with cancer as an adolescent or young adult. *Cancer, 118*(20), 5155-5162. https://doi.org/10.1002/cncr.27512

Benson, J. E., & Elder, G. H., Jr. (2011, Nov). Young adult identities and their pathways: a developmental and life course model. *Dev Psychol, 47*(6), 1646-1657. https://doi.org/10.1037/a0023833

Benton, M. J., Schlairet, M. C., & Gibson, D. R. (2014, Apr). Change in quality of life among breast cancer survivors after resistance training: is there an effect of age? *J Aging Phys Act, 22*(2), 178-185. https://doi.org/10.1123/japa.2012-0227

Berrett-Abebe, J., Cadet, T., Pirl, W., & Lennes, I. (2015). Exploring the Relationship Between Fear of Cancer Recurrence and Sleep Quality in Cancer Survivors. *Journal of Psychosocial Oncology, 33*(3), 297-309. https://doi.org/10.1080/07347332.2015.1020586

Bleyer, A. (2005, May-Jun). The adolescent and young adult gap in cancer care and outcome. *Curr Probl Pediatr Adolesc Health Care, 35*(5), 182-217. https://doi.org/10.1016/j.cppeds.2005.02.001

Box, G. E. P., & Tidwell, P. W. (1962). Transformation of the independent variables. *Technometrics, 4*, 531-550.

Breitbart, W. S., & Alici, Y. (2009). Psycho-oncology. *Harv Rev Psychiatry, 17*(6), 361-376. https://doi.org/10.3109/10673220903465700

Brett, J., Staniszewska, S., Mockford, C., Herron-Marx, S., Hughes, J., Tysall, C., & Suleman, R. (2014, Oct). Mapping the impact of patient and public involvement on health and social care research: a systematic review. *Health Expect, 17*(5), 637-650. https://doi.org/10.1111/j.1369-7625.2012.00795.x

Brierley, M. E., Sansom-Daly, U. M., Baenziger, J., McGill, B., & Wakefield, C. E. (2019, Jul). Impact of physical appearance changes reported by adolescent and young adult cancer survivors: A qualitative analysis. *Eur J Cancer Care (Engl), 28*(4), e13052. https://doi.org/10.1111/ecc.13052

Bujang, M. A., Ghani, P. A., Bujang, M. A., Zolkepali, N. A., Adnan, T. H., Ali, M. M., Selvarajah, S., & Haniff, J. (2012). *A comparison between convenience sampling versus systematic sampling in getting the true parameter in a population: Explore from a clinical database: The Audit Diabetes Control Management (ADCM) registry in 2009* 2012 International Conference on Statistics in Science, Business and Engineering (ICSSBE), Langkawi, Malaysia.

Bultz, B. D., & Carlson, L. E. (2005, Sep 10). Emotional distress: The sixth vital sign in cancer care. *J Clin Oncol, 23*(26), 6440-6441. https://doi.org/10.1200/JCO.2005.02.3259

Burgoyne, M. J., Bingen, K., Leuck, J., Dasgupta, M., Polly Ryan, P., & Hoffmann, R. G. (2015). Cancer-related distress in YAs compared to middle-aged and senior adults. *J Adolesc Young Adult Oncol, 4*(2), 56-63. https://doi.org/10.1089/jayao.2014.0005

Bursac, Z., Gauss, C. H., Williams, D. K., & Hosmer, D. W. (2008, Dec 16). Purposeful selection of variables in logistic regression. *Source Code Biol Med, 3*, 17. https://doi.org/10.1186/1751-0473-3-17

Buysse, D. J., Reynolds III, C. F., Monk, T H., Berman, S. R., & Kupfer, D. J. (1989). The Pittsburgh Sleep Quality Index: A new instrument for psychiatric practice and research. *Psychiatry Res, 28*, 193-213.

Canada, A. L., & Schover, L. R. (2012, Feb). The psychosocial impact of interrupted childbearing in long-term female cancer survivors. *Psychooncology, 21*(2), 134-143. https://doi.org/10.1002/pon.1875

Canadian Community Health Survey - Mental Health (CCHS). (2013). Statistics Canada http://www23.statcan.gc.ca/imdb/p2SV.pl?Function=getSurvey&SDDS=5015

Canadian Institutes of Health Research. (2019, May 2019). *Strategy for Patient-Oriented Research - Patient Engagement Framework*. Retrieved March 15 from http://www.cihr-irsc.gc.ca/e/48413.html

Carlson, L. E., & Bultz, B. D. (2003). Benefits of psychosocial oncology care: Improved quality of life and medical cost offset. *Health and Quality of Life Outcomes, 1*(8). https://doi.org/http://www.hqlo.com/content/1/1/8

Carlson, L. E., & Bultz, B. D. (2004, Dec). Efficacy and medical cost offset of psychosocial interventions in cancer care: making the case for economic analyses. *Psychooncology, 13*(12), 837-849; discussion 850-836. https://doi.org/10.1002/pon.832

Carrera, P. M., Kantarjian, H. M., & Blinder, V. S. (2018, Mar). The financial burden and distress of patients with cancer: Understanding and stepping-up action on the financial toxicity of cancer treatment. *CA Cancer J Clin, 68*(2), 153-165. https://doi.org/10.3322/caac.21443

Cashman, S. B., Adeky, S., Allen, A. J., 3rd, Corburn, J., Israel, B. A., Montano, J., Rafelito, A., Rhodes, S. D., Swanston, S., Wallerstein, N., & Eng, E. (2008, Aug). The power and the promise: working with communities to analyze data, interpret findings, and get to outcomes. *Am J Public Health, 98*(8), 1407-1417. https://doi.org/10.2105/AJPH.2007.113571

Chaplin, T. M. (2015). Gender and emotion expression: A developmental contextual perspective. *Emotion Review, 7*(1), 14-21. https://doi.org/10.1177/1754073914544408

Chiu, C. G., Mitchell, T. L., & Fitch, M. I. (2013, Jun). From patient to participant: enhancing the validity and ethics of cancer research through participatory research. *J Cancer Educ, 28*(2), 237-246. https://doi.org/10.1007/s13187-013-0464-2

Chiu, M., Amartey, A., Wang, X., Vigod, S., & Kurdyak, P. (2020, Mar 30). Trends in objectively measured and perceived mental health and use of mental health services: a population-based study in Ontario, 2002-2014. *CMAJ, 192*(13), E329-E337. https://doi.org/10.1503/cmaj.190603

Clarke, K., Patterson, P., McDonald, F. E. J., Wakefield, C. E., Sansom-Daly, U., & Zebrack, B. (2020). The Development and Process Evaluation of a 3-Day Acceptance and Commitment Therapy Group Program for Adolescent Cancer Survivors. *Child & Youth Care Forum*. https://doi.org/10.1007/s10566-020-09571-4

Cohen, J. (1988). *Statistical power analysis for the behavioral sciences* (2nd ed.). Psychology Press.

Committee on Improving the Health, S., and Well-Being of Young Adults; Board on Children, Youth, and Families; Institute of Medicine; National Research Council. (2015). Investing in the Health and Well-Being of Young Adults. In S. C. Bonnie RJ, Breiner H (Ed.), (pp. 77-122). National Academies Press (US). https://www.ncbi.nlm.nih.gov/books/NBK284783/

Cordova, M. J., Cunningham, L. L. C., Carlson, C. R., & Andrykowski, M. A. (2001). Posttraumatic Growth Following Breast Cancer: A Controlled Comparison Study. *Health Psychology, 20*(3), 176-185. https://doi.org/DOI: I0.1037//0278-6133.20.3.176

Coughlin, K. W. (2018, May). Medical decision-making in paediatrics: Infancy to adolescence. *Paediatr Child Health, 23*(2), 138-146. https://doi.org/10.1093/pch/pxx127

Coyne, I., Prizeman, G., Sheehan, A., Malone, H., & While, A. E. (2016, Sep). An e-health intervention to support the transition of young people with long-term illnesses to adult healthcare services: Design and early use. *Patient Educ Couns, 99*(9), 1496-1504. https://doi.org/10.1016/j.pec.2016.06.005

Crist, J. V., & Grunfeld, E. A. (2013). Factors reported to influence fear of recurrence in cancer patients: a systematic review. *Psycho-Oncology, 22*(5), 978-986. https://doi.org/10.1002/pon.3114

D'Agostino, N. M., & Edelstein, K. (2013). Psychosocial challenges and resource needs of young adult cancer survivors: implications for program development. *J Psychosoc Oncol, 31*(6), 585-600. https://doi.org/10.1080/07347332.2013.835018

Daniel, L., Kazak, A. E., Li, Y., Hobbie, W., Ginsberg, J., Butler, E., & Schwartz, L. (2016, Feb). Relationship between sleep problems and psychological outcomes in adolescent and young adult cancer survivors and controls. *Support Care Cancer, 24*(2), 539-546. https://doi.org/10.1007/s00520-015-2798-2

Dastan, N. B., & Buzlu, S. (2012). Psychoeducation intervention to improve adjustment to cancer among Turkish stage I-II breast cancer patients: a randomized controlled trial. *Asian Pac J Cancer Prev, 13*(10), 5313-5318. https://doi.org/10.7314/apjcp.2012.13.10.5313

de Boer, A. G. E. M., Taskila, T., Ojajärvi, A., van Dijk, F. J. H., & Verbeek, J. H. A. M. (2009). Cancer survivors and unemployment: A meta-analysis and meta-regression. *JAMA, 301*(7), 753-762.

De, R., Zabih, V., Kurdyak, P., Sutradhar, R., Nathan, P. C., McBride, M. L., & Gupta, S. (2020, Feb). Psychiatric Disorders in Adolescent and Young Adult-Onset Cancer Survivors: A Systematic Review and Meta-Analysis. *J Adolesc Young Adult Oncol, 9*(1), 12-22. https://doi.org/10.1089/jayao.2019.0097

Dieng, M., Butow, P. N., Costa, D. S., Morton, R. L., Menzies, S. W., Mireskandari, S., Tesson, S., Mann, G. J., Cust, A. E., & Kasparian, N. A. (2016, Dec 20). Psychoeducational Intervention to Reduce Fear of Cancer Recurrence in People at High Risk of Developing Another Primary Melanoma: Results of a Randomized Controlled Trial. *J Clin Oncol, 34*(36), 4405-4414. https://doi.org/10.1200/JCO.2016.68.2278

Dixon, S. B., Li, N., Yasui, Y., Bhatia, S., Casillas, J. N., Gibson, T. M., Ness, K. K., Porter, J. S., Howell, R. M., Leisenring, W. M., Robison, L. L., Hudson, M. M., Krull, K. R., & Armstrong, G. T. (2019, Oct 15). Racial and ethnic disparities in neurocognitive, emotional, and quality-of-life outcomes in survivors of childhood cancer: A report from the Childhood Cancer Survivor Study. *Cancer, 125*(20), 3666-3677. https://doi.org/10.1002/cncr.32370

Dong, J., & Peng, C. Y. (2013). Principled missing data methods for researchers. *Springerplus, 2*(1). https://doi.org/doi:10.1186/2193-1801-2-222

Edwards, V., Wyatt, K., Logan, S., & Britten, N. (2011, Dec). Consulting parents about the design of a randomized controlled trial of osteopathy for children with cerebral palsy. *Health Expect, 14*(4), 429-438. https://doi.org/10.1111/j.1369-7625.2010.00652.x

Elsbernd, A., Pedersen, K. J., Boisen, K. A., Midtgaard, J., & Larsen, H. B. (2018, Oct). "On Your Own": Adolescent and Young Adult Cancer Survivors' Experience of Managing Return to Secondary or Higher Education in Denmark. *J Adolesc Young Adult Oncol, 7*(5), 618-625. https://doi.org/10.1089/jayao.2018.0058

Eom, C. S., Shin, D. W., Kim, S. Y., Yang, H. K., Jo, H. S., Kweon, S. S., Kang, Y. S., Kim, J. H., Cho, B. L., & Park, J. H. (2013, Jun). Impact of perceived social support on the mental health and health-related quality of life in cancer patients: results from a nationwide, multicenter survey in South Korea. *Psychooncology, 22*(6), 1283-1290. https://doi.org/10.1002/pon.3133

Epelman, C. L. (2013, Aug). The adolescent and young adult with cancer: state of the art -- psychosocial aspects. *Curr Oncol Rep, 15*(4), 325-331. https://doi.org/10.1007/s11912-013-0324-6

Esnaola, N. F., & Ford, M. E. (2012, Jul). Racial differences and disparities in cancer care and outcomes: where's the rub? *Surg Oncol Clin N Am, 21*(3), 417-437, viii. https://doi.org/10.1016/j.soc.2012.03.012

Falk Dahl, C. A., Reinertsen, K. V., Nesvold, I. L., Fossa, S. D., & Dahl, A. A. (2010, Aug 1). A study of body image in long-term breast cancer survivors. *Cancer, 116*(15), 3549-3557. https://doi.org/10.1002/cncr.25251

Fardell, J. E., Jones, G., Smith, A. B., Lebel, S., Thewes, B., Costa, D., Tiller, K., Simard, S., Feldstain, A., Beattie, S., McCallum, M., Conquer Fear authorship, g., & Butow, P. (2018, Feb). Exploring the screening capacity of the Fear of Cancer Recurrence Inventory-Short Form for clinical levels of fear of cancer recurrence. *Psychooncology, 27*(2), 492-499. https://doi.org/10.1002/pon.4516

Fardell, J. E., Thewes, B., Turner, J., Gilchrist, J., Sharpe, L., Smith, A., Girgis, A., & Butow, P. (2016, Aug). Fear of cancer recurrence: a theoretical review and novel cognitive processing formulation. *J Cancer Surviv, 10*(4), 663-673. https://doi.org/10.1007/s11764-015-0512-5

Fitch, M., Zomer, S., Lockwood, G., Louzado, C., Shaw Moxam, R., Rahal, R., & Green, E. (2018). Experiences of adult cancer survivors in transitions. *Supportive Care in Cancer*. https://doi.org/10.1007/s00520-018-4605-3

Forsythe, L. P., Frank, L., Odom Walker, K., Anise, A., Wegener, N., Weisman, H., Hunt, G., & Beal, A. (2015). Patient and clinician views on comparative effectiveness research and engagement in research. *Journal of Comparative Effectiveness, 4*(1), 11-25.

Fullinwider-Bush, N., & Jacobvitz, D. B. (1993). The transition to young adulthood: Generational boundary dissolution and female identity development. *Fam Proc, 32*, 87-103.

Gagnon, P., Fillion, L., Robitaille, M. A., Girard, M., Tardif, F., Cochrane, J. P., Le Moignan Moreau, J., & Breitbart, W. (2015, Aug). A cognitive-existential intervention to improve existential and global quality of life in cancer patients: A pilot study. *Palliat Support Care, 13*(4), 981-990. https://doi.org/10.1017/S147895151400073X

Galan, S., de la Vega, R., Tome Pires, C., Racine, M., Sole, E., Jensen, M. P., & Miro, J. (2017, Mar). What are the needs of adolescents and young adults after a cancer treatment? A Delphi study. *Eur J Cancer Care (Engl), 26*(2). https://doi.org/10.1111/ecc.12488

Goldshmidt, O. T., & Weller, L. (2000). "Talking emotions": Gender differences in a variety of conversational contexts. *Symbolic Interaction, 23*(2), 117-134.

Graham, I. D., Logan, J., Harrison, M. B., Straus, S. E., Tetroe, J., Caswell, W., & Robinson, N. (2006, Winter). Lost in knowledge translation: time for a map? *J Contin Educ Health Prof, 26*(1), 13-24. https://doi.org/10.1002/chp.47

Gupta, A. A., Papadakos, J. K., Jones, J. M., Amin, L., Chang, E. K., Korenblum, C., Santa Mina, D., McCabe, L., Mitchell, L., & Giuliani, M. E. (2016, Apr 1). Reimagining care for adolescent and young adult cancer programs: Moving with the times. *Cancer, 122*(7), 1038-1046. https://doi.org/10.1002/cncr.29834

Guy, G. P., Jr., Yabroff, K. R., Ekwueme, D. U., Smith, A. W., Dowling, E. C., Rechis, R., Nutt, S., & Richardson, L. C. (2014, Jun). Estimating the health and economic burden of cancer among those diagnosed as adolescents and young adults. *Health Aff (Millwood), 33*(6), 1024-1031. https://doi.org/10.1377/hlthaff.2013.1425

Hagstrom, J., Ander, M., Cernvall, M., Ljotsson, B., Wiman, H. W., von Essen, L., & Woodford, J. (2020). Heeding the psychological concerns of young cancer survivors: a single-arm feasibility trial of CBT and a cognitive behavioral conceptualization of distress. *PeerJ, 8*, e8714. https://doi.org/10.7717/peerj.8714

Hair, J. F., Black, W. C., Babin, B. J., Anderson, R. E., & Tatham, R. L. (2006). *Multivariate data analysis*. Pearson Prentice Hall.

Hall, A. E., Boyes, A. W., Bowman, J., Walsh, R. A., James, E. L., & Girgis, A. (2012). Young adult cancer survivors' psychosocial well-being: A cross-sectional study assessing quality of life, unmet needs, and health behaviors. *Support Care Cancer, 20*, 1333-1341. https://doi.org/10.1007/s00520-011-1221-x

Hall, A. E., Sanson-Fisher, R. W., Carey, M. L., Paul, C., Williamson, A., Bradstock, K., & Campbell, H. S. (2016, Oct). Prevalence and associates of psychological distress in haematological cancer survivors. *Support Care Cancer, 24*(10), 4413-4422. https://doi.org/10.1007/s00520-016-3282-3

Haluska, H. B., Jessee, P. O., & Nagy, M. C. (2002, Oct). Sources of social support: adolescents with cancer. *Oncol Nurs Forum, 29*(9), 1317-1324. https://doi.org/10.1188/02.ONF.1317-1324

Hamilton, C. B., Hoens, A. M., Backman, C. L., McKinnon, A. M., McQuitty, S., English, K., & Li, L. C. (2018, Feb). An empirically based conceptual framework for fostering meaningful patient engagement in research. *Health Expect, 21*(1), 396-406. https://doi.org/10.1111/hex.12635

Hanprasertpong, J., Geater, A., Jiamset, I., Padungkul, L., Hirunkajonpan, P., & Songhong, N. (2017, Nov). Fear of cancer recurrence and its predictors among cervical cancer survivors. *J Gynecol Oncol, 28*(6), e72. https://doi.org/10.3802/jgo.2017.28.e72

Hasin, D. S., Sarvet, A. L., Meyers, J. L., Saha, T. D., Ruan, W. J., Stohl, M., & Grant, B. F. (2018, Apr 1). Epidemiology of Adult DSM-5 Major Depressive Disorder and Its Specifiers in the United States. *JAMA Psychiatry, 75*(4), 336-346. https://doi.org/10.1001/jamapsychiatry.2017.4602

Hedman, C., Strang, P., Djarv, T., Widberg, I., & Lundgren, C. I. (2017, Nov). Anxiety and Fear of Recurrence Despite a Good Prognosis: An Interview Study with Differentiated Thyroid Cancer Patients. *Thyroid, 27*(11), 1417-1423. https://doi.org/10.1089/thy.2017.0346

Holland, J. C. (2004, Jul). IPOS Sutherland Memorial Lecture: an international perspective on the development of psychosocial oncology: overcoming cultural and attitudinal barriers to improve psychosocial care. *Psychooncology, 13*(7), 445-459. https://doi.org/10.1002/pon.812

Holland, J. C., & Rowland, J. H. (1989). *Handbook of Psychooncology: Psychological care of the patient with cancer*.

Holtmaat, K., van der Spek, N., Cuijpers, P., Leemans, C. R., & Verdonck-de Leeuw, I. M. (2017, Jan). Posttraumatic growth among head and neck cancer survivors with psychological distress. *Psychooncology, 26*(1), 96-101. https://doi.org/10.1002/pon.4106

Hopwood, P., Fletcher, I., Lee, A., & Ghazal, S. Al. . (2001). A body image scale for use with cancer patients. *Eur J Cancer, 37*.

Horrill, T. C., Linton, J., Lavoie, J. G., Martin, D., Wiens, A., & Schultz, A. S. H. (2019, Oct). Access to cancer care among Indigenous peoples in Canada: A scoping review. *Soc Sci Med, 238*, 112495. https://doi.org/10.1016/j.socscimed.2019.112495

Howell, D., & Olsen, K. (2011). Distress—the 6th vital sign. *Curr Oncol 18*(5), 208-210.

Humphris, G. M., Rogers, S., McNally, D., Lee-Jones, C., Brown, J., & Vaughan, D. (2003). Fear of recurrence and possible cases of anxiety and depression in orofacial cancer patients. . *International Journal of Oral and Maxillofacial Surgery 32*, 486-491. https://doi.org/doi:10.1054/ijom.2002.0399

Jansen, L., Hoffmeister, M., Chang-Claude, J., Brenner, H., & Arndt, V. (2011, Oct 11). Benefit finding and post-traumatic growth in long-term colorectal cancer survivors: prevalence, determinants, and associations with quality of life. *Br J Cancer, 105*(8), 1158-1165. https://doi.org/10.1038/bjc.2011.335

Jorngarden, A., Mattsson, E., & von Essen, L. (2007, Sep). Health-related quality of life, anxiety and depression among adolescents and young adults with cancer: a prospective longitudinal study. *Eur J Cancer, 43*(13), 1952-1958. https://doi.org/10.1016/j.ejca.2007.05.031

Kaul, S., Avila, J. C., Mutambudzi, M., Russell, H., Kirchhoff, A. C., & Schwartz, C. L. (2017, Mar 1). Mental distress and health care use among survivors of adolescent and young adult cancer: A cross-sectional analysis of the National Health Interview Survey. *Cancer, 123*(5), 869-878. https://doi.org/10.1002/cncr.30417

Kazak, A. E., Derosa, B. W., Schwartz, L. A., Hobbie, W., Carlson, C., Ittenbach, R. F., Mao, J. J., & Ginsberg, J. P. (2010, Apr 20). Psychological outcomes and health beliefs in adolescent and young adult survivors of childhood cancer and controls. *J Clin Oncol, 28*(12), 2002-2007. https://doi.org/10.1200/JCO.2009.25.9564

Kazanjian, A., Smillie, K., Howard, A. F., Ward, A., & Doll, R. (2012, Sep). A structured approach to knowledge exchange: understanding the implementation of a cancer survivor program. *Eur J Oncol Nurs, 16*(4), 399-405. https://doi.org/10.1016/j.ejon.2011.09.002

Keegan, T. H. M., Ries, L. A. G., Barr, R. D., Geiger, A. M., Dahlke, D. V., Pollock, B. H., & Bleyer, W. A. (2016). Comparison of cancer survival trends in the United States of adolescents and young adults with those in children and older adults. *Cancer, 122*(7), 1009-1016. https://doi.org/10.1002/cncr.29869

Kessler, R. C., Amminger, P., Aguilar-Gaxiola, S., Alonso, J., Lee, S., & Ustun, T. B. (2007). Age of onset of mental health disorders: A review of recent literature. *Curr Opin Psychiatry, 20*(4), 359-364.

Kessler, R. C., Andrews, G., Colpe, L. J., Hiripi, E., Mroczek, D. K., Normand, S.-L. T., Walters, E. E., & Zalslavsky, A. M. (2002). Short screening scales to monitor population prevalences and trends in non-specific psychological distress. *Psychol Med, 32*, 959–976. https://doi.org/DOI: 10.1017}S0033291702006074

Kessler, R. C., Chiu, W. T., Demler, O., Merikangas, K. R., & Walters, E. E. (2005, Jun). Prevalence, severity, and comorbidity of 12-month DSM-IV disorders in the National Comorbidity Survey Replication. *Arch Gen Psychiatry, 62*(6), 617-627. https://doi.org/10.1001/archpsyc.62.6.617

Kim, G. M., Kim, S. J., Song, S. K., Kim, H. R., Kang, B. D., Noh, S. H., Chung, H. C., Kim, K. R., & Rha, S. Y. (2017, Apr 20). Prevalence and prognostic implications of psychological distress in patients with gastric cancer. *BMC Cancer, 17*(1), 283. https://doi.org/10.1186/s12885-017-3260-2

Koch, L., Jansen, L., Brenner, H., & Arndt, V. (2013, Jan). Fear of recurrence and disease progression in long-term (>/= 5 years) cancer survivors--a systematic review of quantitative studies. *Psychooncology, 22*(1), 1-11. https://doi.org/10.1002/pon.3022

Konstam, V. (2015). Emerging and Young Adulthood: Mulitple Perspectives, Diverse Narratives. *Advancing Responsible Adolescent Development*. https://doi.org/10.1007/978-3-319-11301-2

Kothari, A., McCutcheon, C., & Graham, I. D. (2017, May 1). Defining Integrated Knowledge Translation and Moving Forward: A Response to Recent Commentaries. *Int J Health Policy Manag, 6*(5), 299-300. https://doi.org/10.15171/ijhpm.2017.15

Koyama, A., Matsuoka, H., Ohtake, Y., Makimura, C., Sakai, K., Sakamoto, R., & Murata, M. (2016). Gender differences in cancer-related distress in Japan: a retrospective observation study. *Biopsychosoc Med, 10*, 10. https://doi.org/10.1186/s13030-016-0062-8

Laerd Statistics. (2015). *Independent-samples t-test using SPSS Statistics*. Laerd Statistics. https://statistics.laerd.com/

Laerd Statistics. (2017). *Binomial logistic regression using SPSS Statistics.* Laerd Statistics. https://statistics.laerd.com/

Lampic, C., Ljungman, L., Micaux Obol, C., Eriksson, L. E., & Wettergren, L. (2019, Apr 11). A web-based psycho-educational intervention (Fex-Can) targeting sexual dysfunction and fertility-related distress in young adults with cancer: study protocol of a randomized controlled trial. *BMC Cancer, 19*(1), 344. https://doi.org/10.1186/s12885-019-5518-3

Lang, M. J., David, V., & Giese-Davis, J. (2015, Dec). The age conundrum: A scoping review of younger age or adolescent and young adult as a risk factor for clinical distress, depression, or anxiety in cancer. *J Adolesc Young Adult Oncol, 4*(4), 157-173. https://doi.org/10.1089/jayao.2015.0005

Lang, M. J., Giese-Davis, J., Patton, S. B., & Campbell, D. J. T. (2018). Does age matter? Comparing post-treatment psychosocial outcomes in young adult and older adult cancer survivors with their cancer-free peers. *Psycho-Oncology, 27*, 1404-1411. https://doi.org/10.1002/pon.4490

Lau, J. S., Adams, S. H., Boscardin, W. J., & Irwin, C. E., Jr. (2014, Jun). Young adults' health care utilization and expenditures prior to the Affordable Care Act. *J Adolesc Health, 54*(6), 663-671. https://doi.org/10.1016/j.jadohealth.2014.03.001

Lebel, S., Beattie, S., Ares, I., & Bielajew, C. (2013, Jun). Young and worried: Age and fear of recurrence in breast cancer survivors. *Health Psychol, 32*(6), 695-705. https://doi.org/10.1037/a0030186

Lebel, S., Ozakinci, G., Humphris, G., Mutsaers, B., Thewes, B., Prins, J., Dinkel, A., Butow, P., & University of Ottawa Fear of Cancer Recurrence Colloquium, a. (2016, Aug). From normal response to clinical problem: definition and clinical features of fear of cancer recurrence. *Support Care Cancer, 24*(8), 3265-3268. https://doi.org/10.1007/s00520-016-3272-5

Lebel, S., Tomei, C., Feldstain, A., Beattie, S., & McCallum, M. (2013, Mar). Does fear of cancer recurrence predict cancer survivors' health care use? *Support Care Cancer, 21*(3), 901-906. https://doi.org/10.1007/s00520-012-1685-3

Levant, R. F., Hall, R. J., WIlliams, C. M., & Hasan, N. T. (2009). Gender differences in alexithymia. *Psychology of Men & Masculinity, 10*(3), 190-203.

Lichtenthal, W. G., Corner, G. W., Slivjak, E. T., Roberts, K. E., Li, Y., Breitbart, W., Lacey, S., Tuman, M., DuHamel, K. N., Blinder, V. S., & Beard, C. (2017). A pilot randomized controlled trial of cognitive bias modification to reduce fear of breast cancer recurrence. *Cancer, 123*(8), 1424-1433. https://doi.org/10.1002/cncr.30478

Linden, W., Vodermaier, A., MacKenzie, R., & Greig, D. (2012). Anxiety and depression after cancer diagnosis: Prevalence rates by cancer type, gender, and age. *Journal of Affective Disorders, 141*, 343-351. https://doi.org/10.1016/j.jad.2012.03.025

Liu, J., Peh, C. X., Simard, S., Griva, K., & Mahendran, R. (2018, Aug). Beyond the fear that lingers: The interaction between fear of cancer recurrence and rumination in relation to depression and anxiety symptoms. *J Psychosom Res, 111*, 120-126. https://doi.org/10.1016/j.jpsychores.2018.06.004

Logan, S., Perz, J., Ussher, J. M., Peate, M., & Anazodo, A. (2019, Jan). Systematic review of fertility-related psychological distress in cancer patients: Informing on an improved model of care. *Psychooncology, 28*(1), 22-30. https://doi.org/10.1002/pon.4927

Maher, C. A., Lewis, L. K., Ferrar, K., Marshall, S., De Bourdeaudhuij, I., & Vandelanotte, C. (2014, Feb 14). Are health behavior change interventions that use online social networks effective? A systematic review. *J Med Internet Res, 16*(2), e40. https://doi.org/10.2196/jmir.2952

Mahon, K., Eaton, G., Chalifour, K., Lane, B., Fowler, K., Gambin, L., Clair, L., & Garland, S. N. (In Press 2020). The financial impact of cancer on young adult cancer survivors in canada. *Journal of Cancer Survivorship*.

Martens, T., Rotermund, R., Zu Eulenburg, C., Westphal, M., & Flitsch, J. (2014, Jul). Long-term follow-up and quality of life in patients with intracranial germinoma. *Neurosurg Rev, 37*(3), 445-450; discussion 451. https://doi.org/10.1007/s10143-014-0544-8

Martinez, M. R., & Pasha, A. (2017). Prioritizing mental health research in cancer patients and survivors. *AMA J Ethics, 19*(5), 486-492.

Matsuda, A., Yamaoka, K., Tango, T., Matsuda, T., & Nishimoto, H. (2014, Feb). Effectiveness of psychoeducational support on quality of life in early-stage breast cancer patients: a systematic review and meta-analysis of randomized controlled trials. *Qual Life Res, 23*(1), 21-30. https://doi.org/10.1007/s11136-013-0460-3

Mazereeuw, M. V., Withrow, D. R., Diane Nishri, E., Tjepkema, M., & Marrett, L. D. (2018, Dec). Cancer incidence among First Nations adults in Canada: follow-up of the 1991 Census Mortality Cohort (1992-2009). *Can J Public Health, 109*(5-6), 700-709. https://doi.org/10.17269/s41997-018-0091-0

McCarthy, M. C., McNeil, R., Drew, S., Dunt, D., Kosola, S., Orme, L., & Sawyer, S. M. (2016, Dec). Psychological distress and posttraumatic stress symptoms in adolescents and young adults with cancer and their parents. *J Adolesc Young Adult Oncol, 5*(4), 322-329. https://doi.org/10.1089/jayao.2016.0015

McDonnell, G., Baily, C., Schuler, T., & Verdeli, H. (2015, Apr). Anxiety among adolescent survivors of pediatric cancer: A missing link in the survivorship literature. *Palliat Support Care, 13*(2), 345-349. https://doi.org/10.1017/S1478951514000297

McDonnell, G., Pope, A. W., Schuler, T. A., & Ford, J. S. (2018, Sep). The relationship between cancer-related worry and posttraumatic growth in adolescent and young adult cancer survivors. *Psychooncology, 27*(9), 2155-2164. https://doi.org/10.1002/pon.4785

Mehnert, A., Berg, P., Henrich, G., & Herschbach, P. (2009). Fear of cancer progression and cancer-related intrusive cognitions in breast cancer survivors. *Psycho-Oncology, 18*(12), 1273-1280. https://doi.org/10.1002/pon.1481

Mehnert, A., Hartung, T. J., Friedrich, M., Vehling, S., Brahler, E., Harter, M., Keller, M., Schulz, H., Wegscheider, K., Weis, J., Koch, U., & Faller, H. (2018, Jan). One in two cancer patients is significantly distressed: Prevalence and indicators of distress. *Psychooncology, 27*(1), 75-82. https://doi.org/10.1002/pon.4464

Mehnert, A., Koch, U., Sundermann, C., & Dinkel, A. (2013, Aug). Predictors of fear of recurrence in patients one year after cancer rehabilitation: a prospective study. *Acta Oncol, 52*(6), 1102-1109. https://doi.org/10.3109/0284186X.2013.765063

Mehnert, A., Veers, S., Howaldt, D., Braumann, K. M., Koch, U., & Schulz, K. H. (2011). Effects of a physical exercise rehabilitation group program on anxiety, depression, body image, and health-related quality of life among breast cancer patients. *Onkologie, 34*(5), 248-253. https://doi.org/10.1159/000327813

Melissant, H. C., Neijenhuijs, K. I., Jansen, F., Aaronson, N. K., Groenvold, M., Holzner, B., Terwee, C. B., van Uden-Kraan, C. F., Cuijpers, P., & Verdonck-de Leeuw, I. M. (2018, Jun). A systematic review of the measurement properties of the Body Image Scale (BIS) in cancer patients. *Support Care Cancer, 26*(6), 1715-1726. https://doi.org/10.1007/s00520-018-4145-x

Meyer, T. J., & Mark, M. (1995). Effects of psychosocial interventions with adult cancer patients: A meta-analysis of randomized experiments. *Health Psychol, 14*(2), 101-108.

Moore, S. P., Antoni, S., Colquhoun, A., Healy, B., Ellison-Loschmann, L., Potter, J. D., Garvey, G., & Bray, F. (2015). Cancer incidence in indigenous people in Australia, New Zealand, Canada, and the USA: a comparative population-based study. *The Lancet Oncology, 16*(15), 1483-1492. https://doi.org/10.1016/s1470-2045(15)00232-6

Morris, Z. S., Wooding, S., & Grant, J. (2011, Dec). The answer is 17 years, what is the question: understanding time lags in translational research. *J R Soc Med, 104*(12), 510-520. https://doi.org/10.1258/jrsm.2011.110180

Mutsaers, B., Jones, G., Rutkowski, N., Tomei, C., Seguin Leclair, C., Petricone-Westwood, D., Simard, S., & Lebel, S. (2016, Oct). When fear of cancer recurrence becomes a clinical issue: a qualitative analysis of features associated with clinical fear of cancer recurrence. *Support Care Cancer, 24*(10), 4207-4218. https://doi.org/10.1007/s00520-016-3248-5

Nagelkerke, N. J. D. (1991). A note on a general definition of the coefficient of determination. *Biometrika, 78*(3), 691-692. https://doi.org/https://doi-org.qe2a-proxy.mun.ca/10.1093/biomet/78.3.691

Naik, H., Leung, B., Laskin, J., McDonald, M., Srikanthan, A., Wu, J., Bates, A., & Ho, C. (2020, Jan). Emotional distress and psychosocial needs in patients with breast cancer in British Columbia: younger versus older adults. *Breast Cancer Res Treat, 179*(2), 471-477. https://doi.org/10.1007/s10549-019-05468-6

Ness, S., Kokal, J., Fee-Schroeder, K., Novotny, P., Satele, D., & Barton, D. (2013). Concerns across the survivorship trajectory: Results from a survey of cancer survivors. *Oncol Nurs Forum, 40*, 35-42.

Neville, K. (1998). The relationships among uncertainty, social support, and psychological distress in adolescents recently diagnosed with cancer. *J Pediatr Oncol Nurs, 15*(1), 37-46.

Ngwenya, N., Kenten, C., Jones, L., Gibson, F., Pearce, S., Flatley, M., Hough, R., Stirling, L. C., Taylor, R. M., Wong, G., & Whelan, J. (2017, Jun). Experiences and Preferences for End-of-Life Care for Young Adults with Cancer and Their Informal Carers: A Narrative Synthesis. *J Adolesc Young Adult Oncol, 6*(2), 200-212. https://doi.org/10.1089/jayao.2016.0055

Niedzwiedz, C. L., Knifton, L., Robb, K. A., Katikireddi, S. V., & Smith, D. J. (2019, Oct 11). Depression and anxiety among people living with and beyond cancer: a growing clinical and research priority. *BMC Cancer, 19*(1), 943. https://doi.org/10.1186/s12885-019-6181-4

Nielsen, J. D., Palshof, T., Mainz, J., Jensen, A. B., & Olesen, F. (2003). Randomised controlled trial of a shared care programme for newly referred cancer patients: bridging the gap between general practice and hospital. *Qual Saf Health Car, 12*, 263–272.

Nikbakhsn, N., Moudi, S., Abbasian, S., & Khafri, S. (2014). Prevalence of depression and anxiety among cancer patients. *Caspian J Intern Med, 5*(3).

Nipp, R. D., El-Jawahri, A., D'Arpino, S. M., Chan, A., Fuh, C. X., Johnson, P. C., Lage, D. E., Wong, R. L., Pirl, W. F., Traeger, L., Cashavelly, B. J., Jackson, V. A., Ryan, D. P., Hochberg, E. P., Temel, J. S., & Greer, J. A. (2018, Aug). Symptoms of posttraumatic stress disorder among hospitalized patients with cancer. *Cancer, 124*(16), 3445-3453. https://doi.org/10.1002/cncr.31576

Nissim, R. S., Roth, A., Gupta, A. A., & Elliott, M. (2020, Apr). Mindfulness-Based Cognitive Therapy Intervention for Young Adults with Cancer: A Pilot Mixed-Method Study. *J Adolesc Young Adult Oncol, 9*(2), 256-261. https://doi.org/10.1089/jayao.2019.0086

Nolen-Hoeksema, S. (2000). The role of rumination in depressive disorders and mixed/anxiety/depressive symptoms. *Journal of Abnormal Psychology, 109*(3), 504-511. https://doi.org/DOI: 10.103790021.841X.109.3.504

Nugent, B. D., Bender, C. M., Sereika, S. M., Tersak, J. M., & Rosenzweig, M. (2018, Feb). Cognitive and Occupational Function in Survivors of Adolescent Cancer. *J Adolesc Young Adult Oncol, 7*(1), 79-87. https://doi.org/10.1089/jayao.2017.0043

Odh, I., Lofving, M., & Klaeson, K. (2016, Oct). Existential challenges in young people living with a cancer diagnosis. *Eur J Oncol Nurs, 24*, 54-60. https://doi.org/10.1016/j.ejon.2016.08.005

Ohrnberger, J., Fichera, E., & Sutton, M. (2017, Dec). The relationship between physical and mental health: A mediation analysis. *Soc Sci Med, 195*, 42-49. https://doi.org/10.1016/j.socscimed.2017.11.008

Olsson, M., Enskar, K., Steineck, G., Wilderang, U., & Jarfelt, M. (2018, Jun). Self-Perceived Physical Attractiveness in Relation to Scars Among Adolescent and

Young Adult Cancer Survivors: A Population-Based Study. *J Adolesc Young Adult Oncol, 7*(3), 358-366. https://doi.org/10.1089/jayao.2017.0089

Osborn, R. L., Demoncada, A. C., & Feuerstein, M. (2006). Psychosocial interventions for depression, anxiety, and quality of life in cancer survivors. *International Journal of Psychiatry in Medicine, 36*(1), 13-34.

Ost, L. G. (2014, Oct). The efficacy of Acceptance and Commitment Therapy: an updated systematic review and meta-analysis. *Behav Res Ther, 61*, 105-121. https://doi.org/10.1016/j.brat.2014.07.018

Park, E. M., Check, D. K., Song, M. K., Reeder-Hayes, K. E., Hanson, L. C., Yopp, J. M., Rosenstein, D. L., & Mayer, D. K. (2017, Mar). Parenting while living with advanced cancer: A qualitative study. *Palliat Med, 31*(3), 231-238. https://doi.org/10.1177/0269216316661686

Park, E. M., Deal, A. M., Check, D. K., Hanson, L. C., Reeder-Hayes, K. E., Mayer, D. K., Yopp, J. M., Song, M. K., Muriel, A. C., & Rosenstein, D. L. (2016, Aug). Parenting concerns, quality of life, and psychological distress in patients with advanced cancer. *Psychooncology, 25*(8), 942-948. https://doi.org/10.1002/pon.3935

Park, E. M., & Rosenstein, D. L. (2015). Depression in adolescents and young adults with cancer. *Dialogues Clin Neurosci, 17*(2), 171-180.

Park, E. M., Stephenson, E. M., Moore, C. W., Deal, A. M., & Muriel, A. C. (2019, Jul). Parental psychological distress and cancer stage: A comparison of adults with metastatic and non-metastatic cancer. *Support Care Cancer, 27*(7), 2443-2451. https://doi.org/10.1007/s00520-018-4518-1

Park, M. J., Scott, J. T., Adams, S. H., Brindis, C. D., & Irwin, C. E., Jr. (2014, Jul). Adolescent and young adult health in the United States in the past decade: Little improvement and young adults remain worse off than adolescents. *J Adolesc Health, 55*(1), 3-16. https://doi.org/10.1016/j.jadohealth.2014.04.003

Parsons, H. M., Harlan, L. C., Lynch, C. F., Hamilton, A. S., Wu, X. C., Kato, I., Schwartz, S. M., Smith, A. W., Keel, G., & Keegan, T. H. (2012, Jul 1). Impact of cancer on work and education among adolescent and young adult cancer survivors. *J Clin Oncol, 30*(19), 2393-2400. https://doi.org/10.1200/JCO.2011.39.6333

Patel, V., Flisher, A. J., Hetrick, S., & McGorry, P. (2007). Mental health of young people: a global public-health challenge. *The Lancet, 369*(9569), 1302-1313. https://doi.org/10.1016/s0140-6736(07)60368-7

Petzel, M. Q., Parker, N. H., Valentine, A. D., Simard, S., Nogueras-Gonzalez, G. M., Lee, J. E., Pisters, P. W., Vauthey, J. N., Fleming, J. B., & Katz, M. H. (2012, Dec). Fear of cancer recurrence after curative pancreatectomy: a cross-sectional study in survivors of pancreatic and periampullary tumors. *Ann Surg Oncol, 19*(13), 4078-4084. https://doi.org/10.1245/s10434-012-2566-1

Priede, A., Andreu, Y., Martinez, P., Conchado, A., Ruiz-Torres, M., & Gonzalez-Blanch, C. (2018, May). The factor structure of the Medical Outcomes Study-Social Support Survey: A comparison of different models in a sample of recently diagnosed cancer patients. *J Psychosom Res, 108*, 32-38. https://doi.org/10.1016/j.jpsychores.2018.02.008

Pyke-Grimm, K. A., Franck, L. S., Patterson Kelly, K., Halpern-Felsher, B., Goldsby, R. E., Kleiman, A., & Rehm, R. S. (2019). Treatment decision-making involvement in adolescents and young adults with cancer. *Oncol Nurs Forum, 46*(1), 1-16.

Rabin, C. (2019). Impact of cancer on romantic relationships among young adults: A systematic review. *Journal of Clinical Psychology in Medical Settings, 26*, 1-12. https://doi.org/10.1007/s10880-018-9566-7

Rabin, C., Simpson, N., Morrow, K., & Pinto, B. (2013, Jun). Intervention format and delivery preferences among young adult cancer survivors. *Int J Behav Med, 20*(2), 304-310. https://doi.org/10.1007/s12529-012-9227-4

Raque-Bogdan, T. L., Hoffman, M. A., Ginter, A. C., Piontkowski, S., Schexnayder, K., & White, R. (2015, Oct). The work life and career development of young breast cancer survivors. *J Couns Psychol, 62*(4), 655-669. https://doi.org/10.1037/cou0000068

Rasmussen, D. M., & Elverdam, B. (2008, Dec). The meaning of work and working life after cancer: an interview study. *Psychooncology, 17*(12), 1232-1238. https://doi.org/10.1002/pon.1354

Richter, D., Koehler, M., Friedrich, M., Hilgendorf, I., Mehnert, A., & Weissflog, G. (2015, Sep). Psychosocial interventions for adolescents and young adult cancer patients: A systematic review and meta-analysis. *Crit Rev Oncol Hematol, 95*(3), 370-386. https://doi.org/10.1016/j.critrevonc.2015.04.003

Rippetoe, P. A., & Rogers, R. W. (1987). The effects of components of protection-motivation theory on adpative and maladaptive coping with a health treatment. *Pers Soc Psychol, 52*, 596-604.

Rosenman, R., Tennekoon, V., & Hill, L. G. (2011, Oct). Measuring bias in self-reported data. *Int J Behav Healthc Res, 2*(4), 320-332. https://doi.org/10.1504/IJBHR.2011.043414

Ruscio, A. M., Hallion, L. S., Lim, C. C. W., Aguilar-Gaxiola, S., Al-Hamzawi, A., Alonso, J., Andrade, L. H., Borges, G., Bromet, E. J., Bunting, B., Caldas de Almeida, J. M., Demyttenaere, K., Florescu, S., de Girolamo, G., Gureje, O., Haro, J. M., He, Y., Hinkov, H., Hu, C., de Jonge, P., Karam, E. G., Lee, S., Lepine, J. P., Levinson, D., Mneimneh, Z., Navarro-Mateu, F., Posada-Villa, J., Slade, T., Stein, D. J., Torres, Y., Uda, H., Wojtyniak, B., Kessler, R. C., Chatterji, S., & Scott, K. M. (2017, May 1). Cross-sectional Comparison of the Epidemiology of DSM-5 Generalized Anxiety Disorder Across the Globe. *JAMA Psychiatry, 74*(5), 465-475. https://doi.org/10.1001/jamapsychiatry.2017.0056

Ryan, J., Lopian, L., Le, B., Edney, S., Van Kessel, G., Plotnikoff, R., Vandelanotte, C., Olds, T., & Maher, C. (2019, Jun 24). It's not raining men: a mixed-methods study investigating methods of improving male recruitment to health behaviour research. *BMC Public Health, 19*(1), 814. https://doi.org/10.1186/s12889-019-7087-4

Savard, J., & Ivers, H. (2013, Apr). The evolution of fear of cancer recurrence during the cancer care trajectory and its relationship with cancer characteristics. *J Psychosom Res, 74*(4), 354-360. https://doi.org/10.1016/j.jpsychores.2012.12.013

Secinti, E., Tometich, D. B., Johns, S. A., & Mosher, C. E. (2019, Jul). The relationship between acceptance of cancer and distress: A meta-analytic review. *Clin Psychol Rev, 71*, 27-38. https://doi.org/10.1016/j.cpr.2019.05.001

Seitz, D. C., Besier, T., Debatin, K. M., Grabow, D., Dieluweit, U., Hinz, A., Kaatsch, P., & Goldbeck, L. (2010, Jun). Posttraumatic stress, depression and anxiety among adult long-term survivors of cancer in adolescence. *Eur J Cancer, 46*(9), 1596-1606. https://doi.org/10.1016/j.ejca.2010.03.001

Sharpe, L., Turner, J., Fardell, J. E., Thewes, B., Smith, A. B., Gilchrist, J., Beith, J., Girgis, A., Tesson, S., Day, S., Grunewald, K., Butow, P., & ConquerFear Authorship, g. (2019, Oct). Psychological intervention (ConquerFear) for treating fear of cancer recurrence: mediators and moderators of treatment efficacy. *J Cancer Surviv, 13*(5), 695-702. https://doi.org/10.1007/s11764-019-00788-4

Shay, L. A., Carpentier, M. Y., & Vernon, S. W. (2016, Nov). Prevalence and correlates of fear of recurrence among adolescent and young adult versus older adult post-treatment cancer survivors. *Support Care Cancer, 24*(11), 4689-4696. https://doi.org/10.1007/s00520-016-3317-9

Sherbourne, C. D., & Stewart, A. L. (1991). The MOS Social Support Survey. *Soc Sci Med, 32*(6), 705-714.

Shimizu, K. (2013, May). Effects of integrated psychosocial care for distress in cancer patients. *Jpn J Clin Oncol, 43*(5), 451-457. https://doi.org/10.1093/jjco/hyt024

Short, M. E., Goetzel, R. Z., Pei, X., Tabrizi, M. J., Ozminkowski, R. J., Gibson, T. B., Dejoy, D. M., & Wilson, M. G. (2009, Jul). How accurate are self-reports? Analysis of self-reported health care utilization and absence when compared with administrative data. *J Occup Environ Med, 51*(7), 786-796. https://doi.org/10.1097/JOM.0b013e3181a86671

Siegel, K., Gluhoski, V., & Gorey, E. (1999). Age-Related Distress Among Young Women with Breast Cancer. *Journal of Psychosocial Oncology, 17*(1), 1-20. https://doi.org/10.1300/J077v17n01_01

Simard, S., & Savard, J. (2009, Mar). Fear of Cancer Recurrence Inventory: development and initial validation of a multidimensional measure of fear of cancer recurrence. *Support Care Cancer, 17*(3), 241-251. https://doi.org/10.1007/s00520-008-0444-y

Simard, S., & Savard, J. (2015, Sep). Screening and comorbidity of clinical levels of fear of cancer recurrence. *J Cancer Surviv, 9*(3), 481-491. https://doi.org/10.1007/s11764-015-0424-4

Simard, S., Savard, J., & Ivers, H. (2010, Dec). Fear of cancer recurrence: specific profiles and nature of intrusive thoughts. *J Cancer Surviv, 4*(4), 361-371. https://doi.org/10.1007/s11764-010-0136-8

Simard, S., Thewes, B., Humphris, G., Dixon, M., Hayden, C., Mireskandari, S., & Ozakinci, G. (2013, Sep). Fear of cancer recurrence in adult cancer survivors: a systematic review of quantitative studies. *J Cancer Surviv, 7*(3), 300-322. https://doi.org/10.1007/s11764-013-0272-z

Simonelli, L. E., Siegel, S. D., & Duffy, N. M. (2017, Oct). Fear of cancer recurrence: a theoretical review and its relevance for clinical presentation and management. *Psychooncology, 26*(10), 1444-1454. https://doi.org/10.1002/pon.4168

Simpson, J. S. A., Carlson, L. E., & Trew, M. E. (2001). Effect of Group Therapy for Breast Cancer on Healthcare Utilization. *Cancer Practice, 9*(1), 19-26.

Smrke, A., Leung, B., Srikanthan, A., McDonald, M., Bates, A., & Ho, C. (2020, Aug). Distinct Features of Psychosocial Distress of Adolescents and Young Adults with Cancer Compared to Adults at Diagnosis: Patient-Reported Domains of Concern. *J Adolesc Young Adult Oncol, 9*(4), 540-545. https://doi.org/10.1089/jayao.2019.0157

Statistics Canada. (2020). *Population estimates, quarterly*. Retrieved September 19, 2020 from https://www150.statcan.gc.ca/t1/tbl1/en/tv.action?pid=1710000901

Stava, C. J., Lopez, A., & Vassilopoulou-Sellin, R. (2006, Oct 15). Health profiles of younger and older breast cancer survivors. *Cancer, 107*(8), 1752-1759. https://doi.org/10.1002/cncr.22200

Steinmo, S., Hagger-Johnson, G., & Shahab, L. (2014, Sep). Bidirectional association between mental health and physical activity in older adults: Whitehall II prospective cohort study. *Prev Med, 66*, 74-79. https://doi.org/10.1016/j.ypmed.2014.06.005

Street, R. L., Voigt, B., Geyer, C., Manning, T., & Swanson, G. P. (1995). Increasing patient involvement in choosing treatment for early breast cancer. *Cancer, 76*(11), 2275-2285.

Sun, H., Yang, Y., Zhang, J., Liu, T., Wang, H., Garg, S., & Zhang, B. (2019). Fear of cancer recurrence, anxiety and depressive symptoms in adolescent and young adult cancer patients. *Neuropsychiatr Dis Treat, 15*, 857-865. https://doi.org/10.2147/NDT.S202432

Tauber, N. M., O'Toole, M. S., Dinkel, A., Galica, J., Humphris, G., Lebel, S., Maheu, C., Ozakinci, G., Prins, J., Sharpe, L., Smith, A., Thewes, B., Simard, S., & Zachariae, R. (2019). Effect of psychological intervention on fear of cancer recurrence: A systematic review and meta-analysis. *J Clin Oncol, 37*(31), 2899-2915. https://doi.org/https://doi.org/10.1200/JCO.19.00572

Tedeschi, R. G., & Calhoun, L. G. (1996). The Posttraumatic Growth Inventory: Measuring the positive legacy of trauma. *Journal of Traumatic Stress, 9*(3).

Thewes, B., Bell, M. L., & Butow, P. (2013, Sep). Fear of cancer recurrence in young early-stage breast cancer survivors: the role of metacognitive style and disease-related factors. *Psychooncology, 22*(9), 2059-2063. https://doi.org/10.1002/pon.3252

Thewes, B., Kaal, S. E. J., Custers, J. A. E., Manten-Horst, E., Jansen, R., Servaes, P., van der Graaf, W. T. A., Prins, J. B., & Husson, O. (2018, May). Prevalence and correlates of high fear of cancer recurrence in late adolescents and young adults consulting a specialist adolescent and young adult (AYA) cancer service. *Support Care Cancer, 26*(5), 1479-1487. https://doi.org/10.1007/s00520-017-3975-2

Thornton, C. P., Ruble, K., & Kozachik, S. (2020). Psychosocial interventions for adolescents and young adults with cancer: An integrative review. *J Pediatr Oncol Nurs, 0*(0), 1-15. https://doi.org/10.1177@1043454220919713

Tiggemann, M. (2004). Body image across the adult life span: stability and change. *Body Image, 1*(1), 29-41. https://doi.org/10.1016/s1740-1445(03)00002-0

Understanding Statistics Used to Guide Prognosis and Evaluate Treatment. (2016, March 2016). Retrieved July 30 from https://www.cancer.net/navigating-cancer-care/cancer-basics/understanding-statistics-used-guide-prognosis-and-evaluate-treatment

User's manual for the SF-12v2 Health Survey (2012). (M. E. Maruish, Ed. 3rd ed.). QualityMetric Incorporated.

van de Wal, M., Servaes, P., Berry, R., Thewes, B., & Prins, J. (2018, Dec). Cognitive behavior therapy for fear of cancer recurrence: A case study. *J Clin Psychol Med Settings, 25*(4), 390-407. https://doi.org/10.1007/s10880-018-9545-z van de Wal, M., van de Poll-Franse, L., Prins, J., & Gielissen, M. (2016, Jul). Does fear of cancer recurrence differ between cancer types? A study from the population-based PROFILES registry. *Psychooncology, 25*(7), 772-778. https://doi.org/10.1002/pon.4002

Van der Gucht, K., Takano, K., Labarque, V., Vandenabeele, K., Nolf, N., Kuylen, S., Cosyns, V., Van Broeck, N., Kuppens, P., & Raes, F. (2017, Jun). A Mindfulness-Based Intervention for Adolescents and Young Adults After Cancer Treatment: Effects on Quality of Life, Emotional Distress, and Cognitive Vulnerability. *J Adolesc Young Adult Oncol, 6*(2), 307-317. https://doi.org/10.1089/jayao.2016.0070

Walker, E., Martins, A., Aldiss, S., Gibson, F., & Taylor, R. M. (2016, Dec). Psychosocial Interventions for Adolescents and Young Adults Diagnosed with Cancer During Adolescence: A Critical Review. *J Adolesc Young Adult Oncol, 5*(4), 310-321. https://doi.org/10.1089/jayao.2016.0025

Wang, K. S., Liu, X., & Wang, L. (2014). Age and gender differences in association between serious psychological distress and cancer. *AM J Cancer Sci, 3*(1), 54-66.

Wang, R., Syed, I. A., Nathan, P. C., Barr, R. D., Rosenberg-Yunger, Z. R., & Klassen, A. F. (2015, Dec). Exploring Cancer Worry in Adolescent and Young Adult Survivors of Childhood Cancers. *J Adolesc Young Adult Oncol, 4*(4), 192-199. https://doi.org/10.1089/jayao.2015.0029

Ware, J. E., Kosinski, M., & Keller, S. D. (1996). A 12-Item short-form health survey: Construction of scales and preliminary tests of reliability and validity. *Medical Care, 34*(3), 220-233.

Watson, M., Dunn, J., & Holland, J. C. (2014, Feb). Review of the history and development in the field of psychosocial oncology. *Int Rev Psychiatry, 26*(1), 128-135. https://doi.org/10.3109/09540261.2013.849230

Wilder Smith, A., Bellizzi, K. M., Keegan, T. H. M., Zebrack, B., Chen, V. W., Neale, A. V., Hamilton, A. S., Shnorhavorian, M., & Lynch, C. F. (2013). Health-related quality of life of adolescent and young adult patients with cancer in the United States: The adolescent and young adult health outcomes and patient experience study. *J Clin Oncol, 31*(17), 2136-2145. https://doi.org/10.1200/jco.2012.47.3173

Wilford, J., Buchbinder, D., Fortier, M.A., Osann, K., Shen, V., Torno, L., Sender, L. S., Parsons, S. K., & Wenzel, L. (2017). "She was a little social butterfly": A qualitative analysis of parent perception of social functioning in adolescent and young adult brain tumor survivors. *J Pediatr Oncol Nurs, 34*(4), 239-249. https://doi.org/10.1177/1043454216688660

Withrow, D. R., Pole, J. D., Nishri, E. D., Tjepkema, M., & Marrett, L. D. (2017, Jan). Cancer Survival Disparities Between First Nation and Non-Aboriginal Adults in Canada: Follow-up of the 1991 Census Mortality Cohort. *Cancer Epidemiol Biomarkers Prev, 26*(1), 145-151. https://doi.org/10.1158/1055-9965.EPI-16-0706

Wright, M. J., Overton, H. N., Teinor, J. A., Ding, D., Burkhart, R. A., Cameron, J. L., He, J., Wolfgang, C. L., Weiss, M. J., & Javed, A. A. (2020, Jul). Disparities in the Use of Chemotherapy in Patients with Resected Pancreatic Ductal Adenocarcinoma. *J Gastrointest Surg, 24*(7), 1590-1596. https://doi.org/10.1007/s11605-019-04311-z

Wu, P.-H., Chen, S.-W., Huang, W.-T., Chang, S.-C., & Hsu, M.-C. (2018). Effects of a psychoeducational intervention in patients with breast cancer undergoing chemotherapy. *Journal of Nursing Research, 0*(0). https://doi.org/10.1097/jnr.0000000000000252

Yang, Y., Li, W., Wen, Y., Wang, H., Sun, H., Liang, W., Zhang, B., & Humphris, G. (2019, Apr). Fear of cancer recurrence in adolescent and young adult cancer survivors: A systematic review of the literature. *Psychooncology, 28*(4), 675-686. https://doi.org/10.1002/pon.5013

Yang, Y., Wen, Y., Bedi, C., & Humphris, G. (2017, Jul). The relationship between cancer patient's fear of recurrence and chemotherapy: A systematic review and meta-analysis. *J Psychosom Res, 98*, 55-63. https://doi.org/10.1016/j.jpsychores.2017.05.002

Young Adult Cancer Canada. (2014). https://www.youngadultcancer.ca/moving-beyond-cancer/

Zebrack, B., Kwak, M., Salsman, J., Cousino, M., Meeske, K., Aguilar, C., Embry, L., Block, R., Hayes-Lattin, B., & Cole, S. (2015, Feb). The relationship between posttraumatic stress and posttraumatic growth among adolescent and young adult (AYA) cancer patients. *Psychooncology, 24*(2), 162-168. https://doi.org/10.1002/pon.3585

Zebrack, B., Mills, J., & Weitzman, T. S. (2007, Jun). Health and supportive care needs of young adult cancer patients and survivors. *J Cancer Surviv, 1*(2), 137-145. https://doi.org/10.1007/s11764-007-0015-0

Zirkel, S., & Cantor, N. (1990). Personal construal of life tasks: Those who struggle for independence. *J Pers Soc Psychol, 58*(1), 172-185.

Zucchetti, G., Bellini, S., Bertolotti, M., Bona, F., Biasin, E., Bertorello, N., Tirtei, E., & Fagioli, F. (2017, Jun). Body Image Discomfort of Adolescent and Young Adult Hematologic Cancer Survivors. *J Adolesc Young Adult Oncol, 6*(2), 377-380. https://doi.org/10.1089/jayao.2016.0067

Appendices

Appendix A. Permission for use of distress publication.

SPRINGER NATURE LICENSE
TERMS AND CONDITIONS

Sep 24, 2020

This Agreement between Miss. Breanna Lane ("You") and Springer Nature ("Springer Nature") consists of your license details and the terms and conditions provided by Springer Nature and Copyright Clearance Center.

License Number	4915480823959
License date	Sep 24, 2020
Licensed Content Publisher	Springer Nature
Licensed Content Publication	Supportive Care in Cancer
Licensed Content Title	Prevalence and factors associated with high levels of distress in young adult cancer survivors compared to matched peers
Licensed Content Author	Breanna Lane et al.
Licensed Content Date	Sep 24, 2020
Type of Use	Thesis/Dissertation
Requestor type	academic/university or research institute
Format Portion	electronic
Portion full	article/chapter
Will you be translating?	No
Circulation/distribution	1-29
Author of this Springer Nature content	Yes
Title	Prevalence and factors associated with high levels

	of distress in young adult cancer survivors compared to matched peers
Institution name	Memorial University of Newfoundland
Expected presentation date	Nov 2020
Requestor Location	Miss Breanna Lane 1044 Greenwood Ave. Halifax, NS B3H3L2 Canada
Total	0.0 CAD

Terms and Conditions

Springer Nature Customer Service Centre GmbH Terms and Conditions

This agreement sets out the terms and conditions of the licence (the **Licence**) between you and **Springer Nature Customer Service Centre GmbH** (the **Licensor**). By clicking 'accept' and completing the transaction for the material (**Licensed Material**), you also confirm your acceptance of these terms and conditions.

1. Grant of License

1. 1. The Licensor grants you a personal, non-exclusive, non-transferable, world-wide licence to reproduce the Licensed Material for the purpose specified in your order only. Licences are granted for the specific use requested in the order and for no other use, subject to the conditions below.

1. 2. The Licensor warrants that it has, to the best of its knowledge, the rights to license reuse of the Licensed Material. However, you should ensure that the material you are requesting is original to the Licensor and does not carry the copyright of another entity (as credited in the published version).

1. 3. If the credit line on any part of the material you have requested indicates that it was reprinted or adapted with permission from another source, then you should also seek permission from that source to reuse the material.

2. Scope of Licence

2. 1. You may only use the Licensed Content in the manner and to the extent permitted by these Ts&Cs and any applicable laws.

2. 2. A separate licence may be required for any additional use of the Licensed

Material, e.g. where a licence has been purchased for print only use, separate permission must be obtained for electronic re-use. Similarly, a licence is only valid in the language selected and does not apply for editions in other languages unless additional translation rights have been granted separately in the licence. Any content owned by third parties are expressly excluded from the licence.

2. 3. Similarly, rights for additional components such as custom editions and derivatives require additional permission and may be subject to an additional fee. Please apply to Journalpermissions@springernature.com/bookpermissions@springernature.com for these rights.

2. 4. Where permission has been granted **free of charge** for material in print, permission may also be granted for any electronic version of that work, provided that the material is incidental to your work as a whole and that the electronic version is essentially equivalent to, or substitutes for, the print version.

2. 5. An alternative scope of licence may apply to signatories of the STM Permissions Guidelines, as amended from time to time.

3. Duration of Licence

3. 1. A licence for is valid from the date of purchase ('Licence Date') at the end of the relevant period in the below table:

Scope of Licence	**Duration of Licence**
Post on a Website	12 months
Presentations	12 months
Books and journals	Lifetime of the edition in the language purchased

4. Acknowledgement

4. 1. The Licensor's permission must be acknowledged next to the Licenced Material in print. In electronic form, this acknowledgement must be visible at the same time as the figures/tables/illustrations or abstract, and must be hyperlinked to the journal/book's homepage. Our required acknowledgement format is in the Appendix below.

5. Restrictions on use

5. 1. Use of the Licensed Material may be permitted for incidental promotional use and minor editing privileges e.g. minor adaptations of single figures, changes of format, colour and/or style where the adaptation is credited as set out in

Appendix 1 below. Any other changes including but not limited to, cropping, adapting, omitting material that affect the meaning, intention or moral rights of the author are strictly prohibited.

5. 2. You must not use any Licensed Material as part of any design or trademark.

5. 3. Licensed Material may be used in Open Access Publications (OAP) before publication by Springer Nature, but any Licensed Material must be removed from OAP sites prior to final publication.

6. Ownership of Rights

6. 1. Licensed Material remains the property of either Licensor or the relevant third party and any rights not explicitly granted herein are expressly reserved.

7. Warranty

IN NO EVENT SHALL LICENSOR BE LIABLE TO YOU OR ANY OTHER PARTY OR ANY OTHER PERSON OR FOR ANY SPECIAL, CONSEQUENTIAL, INCIDENTAL OR INDIRECT DAMAGES, HOWEVER CAUSED, ARISING OUT OF OR IN CONNECTION WITH THE DOWNLOADING, VIEWING OR USE OF THE MATERIALS REGARDLESS OF THE FORM OF ACTION, WHETHER FOR BREACH OF CONTRACT, BREACH OF WARRANTY, TORT, NEGLIGENCE, INFRINGEMENT OR OTHERWISE (INCLUDING, WITHOUT LIMITATION, DAMAGES BASED ON LOSS OF PROFITS, DATA, FILES, USE, BUSINESS OPPORTUNITY OR CLAIMS OF THIRD PARTIES), AND WHETHER OR NOT THE PARTY HAS BEEN ADVISED OF THE POSSIBILITY OF SUCH DAMAGES. THIS LIMITATION SHALL APPLY NOTWITHSTANDING ANY FAILURE OF ESSENTIAL PURPOSE OF ANY LIMITED REMEDY PROVIDED HEREIN.

8. Limitations

8. 1. ***BOOKS ONLY:*** Where **'reuse in a dissertation/thesis'** has been selected the following terms apply: Print rights of the final author's accepted manuscript (for clarity, NOT the published version) for up to 100 copies, electronic rights for use only on a personal website or institutional repository as defined by the Sherpa guideline (www.sherpa.ac.uk/romeo/).

9. Termination and Cancellation

9. 1. Licences will expire after the period shown in Clause 3 (above).
9. 2. Licensee reserves the right to terminate the Licence in the event that payment is not received in full or if there has been a breach of this agreement by you.

Appendix 1 — Acknowledgements:

For Journal Content:
Reprinted by permission from [**the Licensor**]: [**Journal Publisher** (e.g. Nature/Springer/Palgrave)] [**JOURNAL NAME**] [**REFERENCE CITATION** (Article name, Author(s) Name), [**COPYRIGHT**] (year of publication)

For **Advance Online Publication papers:**
Reprinted by permission from [**the Licensor**]: [**Journal Publisher** (e.g. Nature/Springer/Palgrave)] [**JOURNAL NAME**] [**REFERENCE CITATION** (Article name, Author(s) Name), [**COPYRIGHT**] (year of publication), advance online publication, day month year (doi: 10.1038/sj.[JOURNAL ACRONYM].)

For Adaptations/Translations:
Adapted/Translated by permission from [**the Licensor**]: [**Journal Publisher** (e.g. Nature/Springer/Palgrave)] [**JOURNAL NAME**] [**REFERENCE CITATION** (Article name, Author(s) Name), [**COPYRIGHT**] (year of publication)

Note: For any republication from the British Journal of Cancer, the following credit line style applies:

Reprinted/adapted/translated by permission from [**the Licensor**]: on behalf of Cancer Research UK: : [**Journal Publisher** (e.g. Nature/Springer/Palgrave)] [**JOURNAL NAME**] [**REFERENCE CITATION** (Article name, Author(s) Name), [**COPYRIGHT]** (year of publication)

For **Advance Online Publication** papers:
Reprinted by permission from The [**the Licensor**]: on behalf of Cancer Research UK: [**Journal Publisher** (e.g. Nature/Springer/Palgrave)] [**JOURNAL NAME**] [**REFERENCE CITATION** (Article name, Author(s) Name), [**COPYRIGHT**] (year of publication), advance online publication, day month year (doi: 10.1038/sj. [JOURNAL ACRONYM])

For Book content:
Reprinted/adapted by permission from [**the Licensor**]: [**Book Publisher** (e.g. Palgrave Macmillan, Springer etc) [**Book Title**] by [**Book author**(s)] [**COPYRIGHT**] (year of publication)

Other Conditions:

Version 1.2
Questions? customercare@copyright.com or +1-855-239-3415 (toll free in the US) or +1-978-646-2777.

Appendix B. Permission for use of FCR publication.

SPRINGER NATURE LICENSE
TERMS AND CONDITIONS

Sep 23, 2020

This Agreement between Miss. Breanna Lane ("You") and Springer Nature ("Springer Nature") consists of your license details and the terms and conditions provided by Springer Nature and Copyright Clearance Center.

License Number	914891151443
License date	Sep 23, 2020
Licensed Content Publisher	Springer Nature
Licensed Content Publication	Journal of Cancer Survivorship
Licensed Content Title	Prevalence and factors associated with fear of recurrence in a mixed sample of young adults with cancer
Licensed Content Author	Breanna E. Lane et al.
Licensed Content Date	Aug 29, 2019
Type of Use	Thesis/Dissertation
Requestor type	academic/university or research institute
Format Portion	electronic
Portion full	article/chapter
Will you be translating?	No
Circulation/distribution	1-29
Author of this Springer Nature content	Yes

Title	Prevalence and factors associated with fear of recurrence in a mixed sample of young adults with cancer
Institution name	Memorial University of Newfoundland
Expected presentation date	Sep 2020
Requestor Location	Miss Breanna Lane 1044 Greenwood Ave. Halifax, NS B3H3L2 Canada
Total	0.0 CAD

Terms and Conditions

Springer Nature Customer Service Centre GmbH Terms and Conditions

This agreement sets out the terms and conditions of the licence (the **Licence**) between you and **Springer Nature Customer Service Centre GmbH** (the **Licensor**). By clicking 'accept' and completing the transaction for the material (**Licensed Material**), you also confirm your acceptance of these terms and conditions.

1. Grant of License

1. 1. The Licensor grants you a personal, non-exclusive, non-transferable, world-wide licence to reproduce the Licensed Material for the purpose specified in your order only. Licences are granted for the specific use requested in the order and for no other use, subject to the conditions below.

1. 2. The Licensor warrants that it has, to the best of its knowledge, the rights to license reuse of the Licensed Material. However, you should ensure that the material you are requesting is original to the Licensor and does not carry the copyright of another entity (as credited in the published version).

1. 3. If the credit line on any part of the material you have requested indicates that it was reprinted or adapted with permission from another source, then you should also seek permission from that source to reuse the material.

2. Scope of Licence

2. 1. You may only use the Licensed Content in the manner and to the extent permitted by these Ts&Cs and any applicable laws.

2. 2. A separate licence may be required for any additional use of the Licensed Material, e.g. where a licence has been purchased for print only use, separate permission must be obtained for electronic re-use. Similarly, a licence is only valid in the language selected and does not apply for editions in other languages unless additional translation rights have been granted separately in the licence. Any content owned by third parties are expressly excluded from the licence.

2. 3. Similarly, rights for additional components such as custom editions and derivatives require additional permission and may be subject to an additional fee. Please apply to Journalpermissions@springernature.com/bookpermissions@springernature.com for these rights.

2. 4. Where permission has been granted **free of charge** for material in print, permission may also be granted for any electronic version of that work, provided that the material is incidental to your work as a whole and that the electronic version is essentially equivalent to, or substitutes for, the print version.

2. 5. An alternative scope of licence may apply to signatories of the STM Permissions Guidelines, as amended from time to time.

3. Duration of Licence

3. 1. A licence for is valid from the date of purchase ('Licence Date') at the end of the relevant period in the below table:

Scope of Licence	**Duration of Licence**
Post on a Website	12 months
Presentations	12 months
Books and journals	Lifetime of the edition in the language purchased

4. Acknowledgement

4. 1. The Licensor's permission must be acknowledged next to the Licenced Material in print. In electronic form, this acknowledgement must be visible at the same time as the figures/tables/illustrations or abstract, and must be hyperlinked to the journal/book's homepage. Our required acknowledgement format is in the Appendix below.

5. Restrictions on use

5. 1. Use of the Licensed Material may be permitted for incidental promotional use and minor editing privileges e.g. minor adaptations of single figures, changes of format, colour and/or style where the adaptation is credited as set out in Appendix 1 below. Any other changes including but not limited to, cropping, adapting, omitting material that affect the meaning, intention or moral rights of the author are strictly prohibited.

5. 2. You must not use any Licensed Material as part of any design or trademark.

5. 3. Licensed Material may be used in Open Access Publications (OAP) before publication by Springer Nature, but any Licensed Material must be removed from OAP sites prior to final publication.

6. Ownership of Rights

6. 1. Licensed Material remains the property of either Licensor or the relevant third party and any rights not explicitly granted herein are expressly reserved.

7. Warranty

IN NO EVENT SHALL LICENSOR BE LIABLE TO YOU OR ANY OTHER PARTY OR ANY OTHER PERSON OR FOR ANY SPECIAL, CONSEQUENTIAL, INCIDENTAL OR INDIRECT DAMAGES, HOWEVER CAUSED, ARISING OUT OF OR IN CONNECTION WITH THE DOWNLOADING, VIEWING OR USE OF THE MATERIALS REGARDLESS OF THE FORM OF ACTION, WHETHER FOR BREACH OF CONTRACT, BREACH OF WARRANTY, TORT, NEGLIGENCE, INFRINGEMENT OR OTHERWISE (INCLUDING, WITHOUT LIMITATION, DAMAGES BASED ON LOSS OF PROFITS, DATA, FILES, USE, BUSINESS OPPORTUNITY OR CLAIMS OF THIRD PARTIES), AND WHETHER OR NOT THE PARTY HAS BEEN ADVISED OF THE POSSIBILITY OF SUCH DAMAGES. THIS LIMITATION SHALL APPLY NOTWITHSTANDING ANY FAILURE OF ESSENTIAL PURPOSE OF ANY LIMITED REMEDY PROVIDED HEREIN.

8. Limitations

8. 1. ***BOOKS ONLY:*** Where **'reuse in a dissertation/thesis'** has been selected the following terms apply: Print rights of the final author's accepted manuscript (for clarity, NOT the published version) for up to 100 copies, electronic rights for use only on a personal website or institutional repository as defined by the Sherpa guideline (www.sherpa.ac.uk/romeo/).

9. Termination and Cancellation

9. 1. Licences will expire after the period shown in Clause 3 (above).
9. 2. Licensee reserves the right to terminate the Licence in the event that payment is not received in full or if there has been a breach of this agreement by you.

Appendix 1 — Acknowledgements:

For Journal Content:
Reprinted by permission from [**the Licensor**]: [**Journal Publisher** (e.g. Nature/Springer/Palgrave)] [**JOURNAL NAME**] [**REFERENCE CITATION** (Article name, Author(s) Name), [**COPYRIGHT**] (year of publication)

For **Advance Online Publication papers:**
Reprinted by permission from [**the Licensor**]: [**Journal Publisher** (e.g. Nature/Springer/Palgrave)] [**JOURNAL NAME**] [**REFERENCE CITATION** (Article name, Author(s) Name), [**COPYRIGHT**] (year of publication), advance online publication, day month year (doi: 10.1038/sj.[JOURNAL ACRONYM].)

For Adaptations/Translations:
Adapted/Translated by permission from [**the Licensor**]: [**Journal Publisher** (e.g. Nature/Springer/Palgrave)] [**JOURNAL NAME**] [**REFERENCE CITATION** (Article name, Author(s) Name), [**COPYRIGHT**] (year of publication)

Note: For any republication from the British Journal of Cancer, the following credit line style applies:

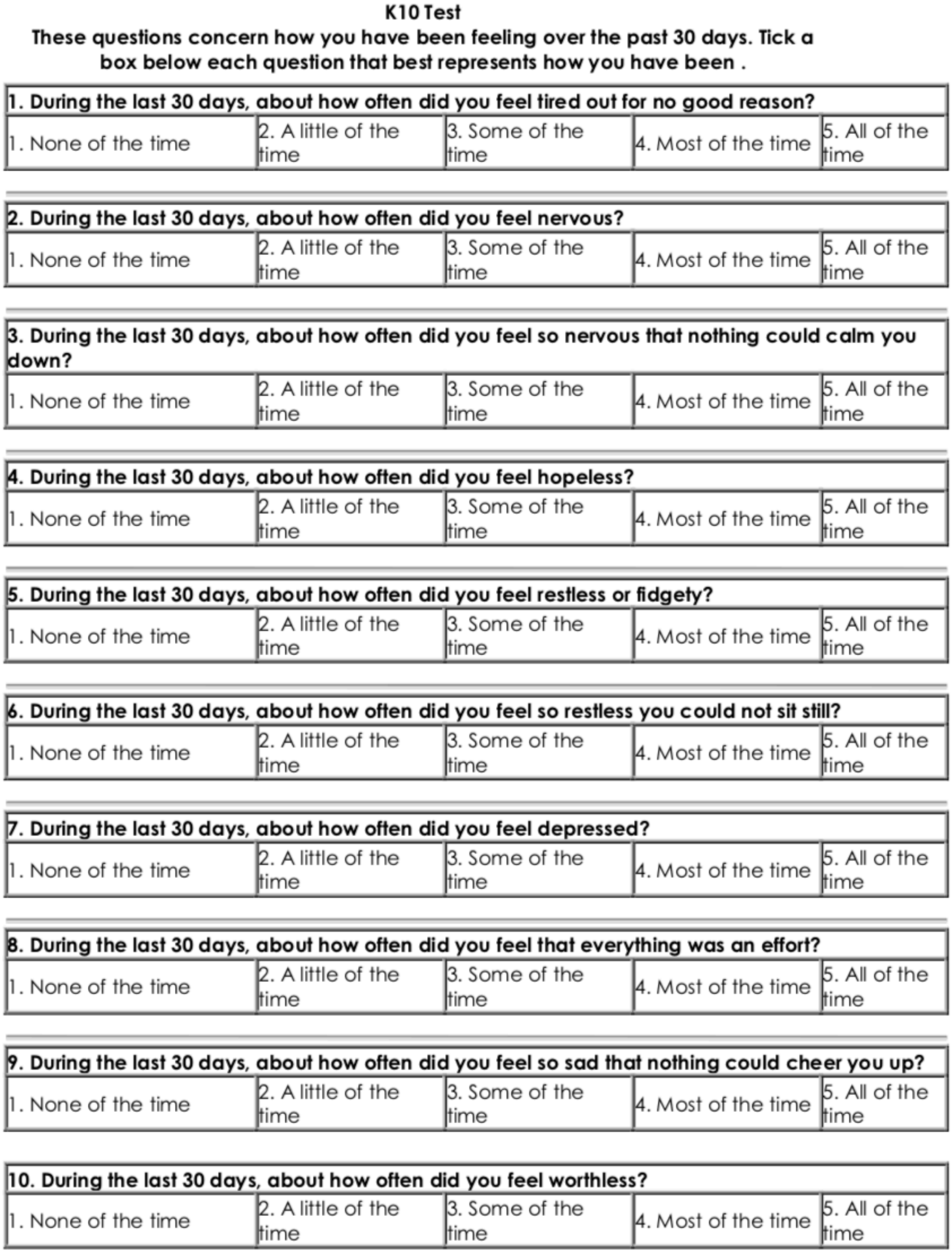
Reprinted/adapted/translated by permission from [**the Licensor**]: on behalf of Cancer Research UK: [**Journal Publisher** (e.g. Nature/Springer/Palgrave)] [**JOURNAL NAME**] [**REFERENCE CITATION** (Article name, Author(s) Name), [**COPYRIGHT]** (year of publication)

For **Advance Online Publication** papers:
Reprinted by permission from The [**the Licensor**]: on behalf of Cancer Research UK: [**Journal Publisher** (e.g. Nature/Springer/Palgrave)] [**JOURNAL NAME**] [**REFERENCE CITATION** (Article name, Author(s) Name), [**COPYRIGHT**] (year of publication), advance online publication, day month year (doi: 10.1038/sj. [JOURNAL ACRONYM])

For Book content:
Reprinted/adapted by permission from [**the Licensor**]: [**Book Publisher** (e.g. Palgrave Macmillan, Springer etc) [**Book Title**] by [**Book author**(s)] [**COPYRIGHT**] (year of publication)

Other Conditions:

Appendix C. Kessler Psychological Distress Scale 10.



K10 Test

These questions concern how you have been feeling over the past 30 days. Tick a box below each question that best represents how you have been .

1. During the last 30 days, about how often did you feel tired out for no good reason?				
1. None of the time	2. A little of the time	3. Some of the time	4. Most of the time	5. All of the time

2. During the last 30 days, about how often did you feel nervous?				
1. None of the time	2. A little of the time	3. Some of the time	4. Most of the time	5. All of the time

3. During the last 30 days, about how often did you feel so nervous that nothing could calm you down?				
1. None of the time	2. A little of the time	3. Some of the time	4. Most of the time	5. All of the time

4. During the last 30 days, about how often did you feel hopeless?				
1. None of the time	2. A little of the time	3. Some of the time	4. Most of the time	5. All of the time

5. During the last 30 days, about how often did you feel restless or fidgety?				
1. None of the time	2. A little of the time	3. Some of the time	4. Most of the time	5. All of the time

6. During the last 30 days, about how often did you feel so restless you could not sit still?				
1. None of the time	2. A little of the time	3. Some of the time	4. Most of the time	5. All of the time

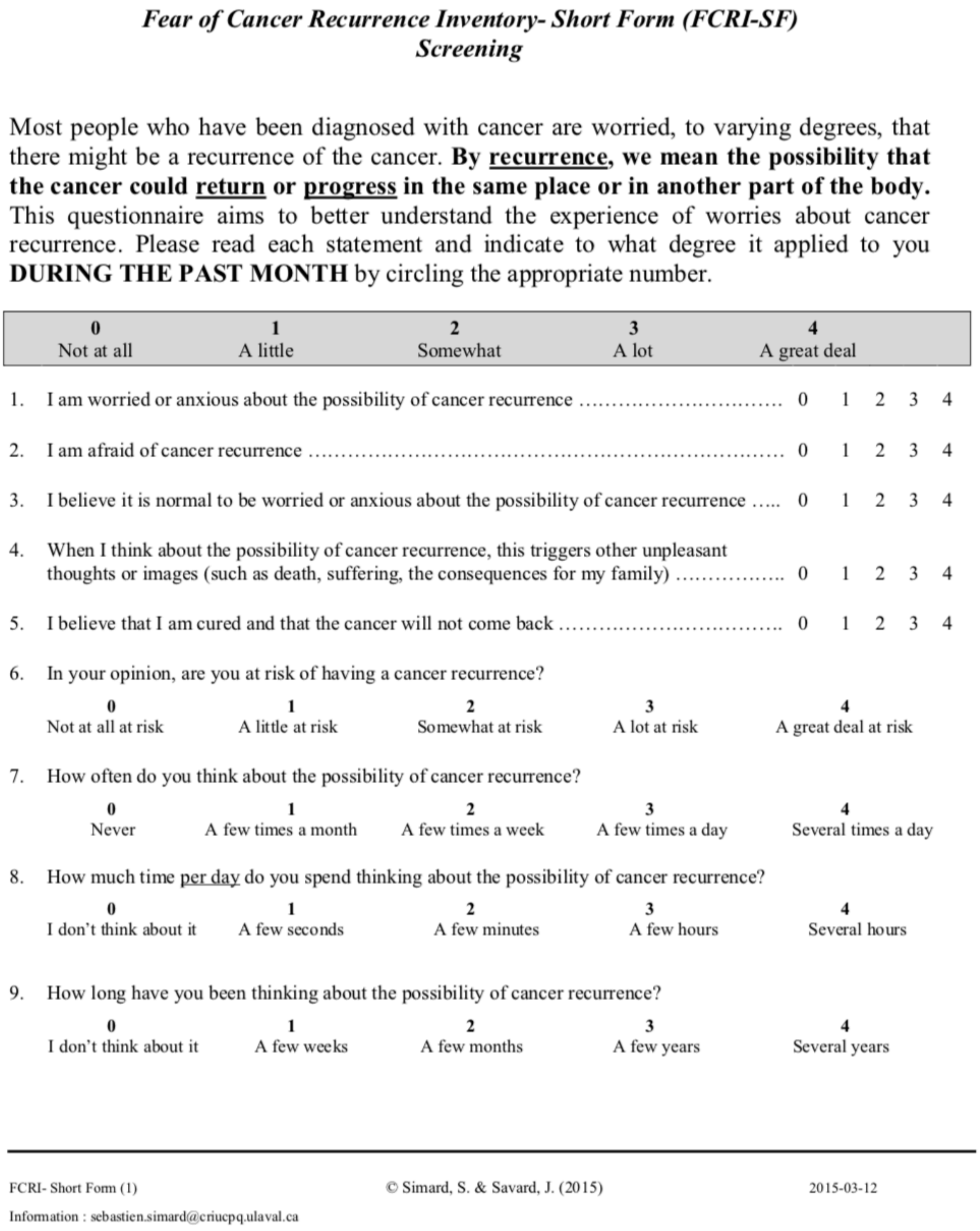
7. During the last 30 days, about how often did you feel depressed?				
1. None of the time	2. A little of the time	3. Some of the time	4. Most of the time	5. All of the time

8. During the last 30 days, about how often did you feel that everything was an effort?				
1. None of the time	2. A little of the time	3. Some of the time	4. Most of the time	5. All of the time

9. During the last 30 days, about how often did you feel so sad that nothing could cheer you up?				
1. None of the time	2. A little of the time	3. Some of the time	4. Most of the time	5. All of the time

10. During the last 30 days, about how often did you feel worthless?				
1. None of the time	2. A little of the time	3. Some of the time	4. Most of the time	5. All of the time

Appendix D. Fear of Cancer Recurrence Inventory – Short Form.



Fear of Cancer Recurrence Inventory- Short Form (FCRI-SF)
Screening

Most people who have been diagnosed with cancer are worried, to varying degrees, that there might be a recurrence of the cancer. **By <u>recurrence</u>, we mean the possibility that the cancer could <u>return</u> or <u>progress</u> in the same place or in another part of the body.** This questionnaire aims to better understand the experience of worries about cancer recurrence. Please read each statement and indicate to what degree it applied to you **DURING THE PAST MONTH** by circling the appropriate number.

0	**1**	**2**	**3**	**4**
Not at all	A little	Somewhat	A lot	A great deal

1.	I am worried or anxious about the possibility of cancer recurrence ………………………….	0	1	2	3	4
2.	I am afraid of cancer recurrence ……………………………………………………………….	0	1	2	3	4
3.	I believe it is normal to be worried or anxious about the possibility of cancer recurrence …..	0	1	2	3	4
4.	When I think about the possibility of cancer recurrence, this triggers other unpleasant thoughts or images (such as death, suffering, the consequences for my family) ……………..	0	1	2	3	4
5.	I believe that I am cured and that the cancer will not come back ……………………………..	0	1	2	3	4

6. In your opinion, are you at risk of having a cancer recurrence?

0	**1**	**2**	**3**	**4**
Not at all at risk	A little at risk	Somewhat at risk	A lot at risk	A great deal at risk

7. How often do you think about the possibility of cancer recurrence?

0	**1**	**2**	**3**	**4**
Never	A few times a month	A few times a week	A few times a day	Several times a day

8. How much time <u>per day</u> do you spend thinking about the possibility of cancer recurrence?

0	**1**	**2**	**3**	**4**
I don't think about it	A few seconds	A few minutes	A few hours	Several hours

9. How long have you been thinking about the possibility of cancer recurrence?

0	**1**	**2**	**3**	**4**
I don't think about it	A few weeks	A few months	A few years	Several years

FCRI- Short Form (1) © Simard, S. & Savard, J. (2015) 2015-03-12

Information : sebastien.simard@criucpq.ulaval.ca

Appendix E. Body Image Scale.

BODY IMAGE SCALE

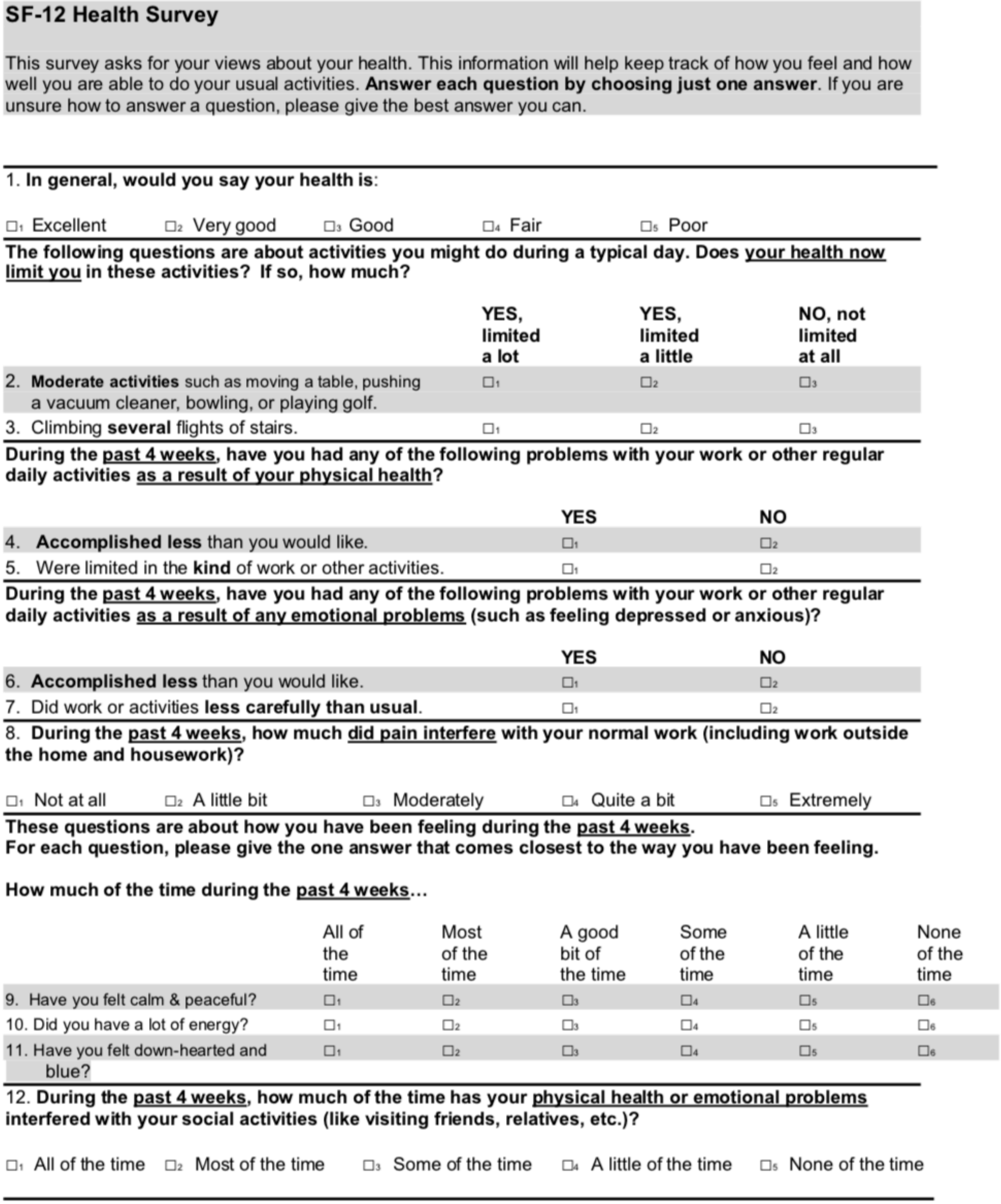
In this questionnaire you will be asked how you feel about your appearance, and about any changes that may have resulted from your disease or treatment. Please read each item carefully, and place a firm tick on the line alongside the reply which comes closest to the way you have been feeling about yourself, during the past week.

Name: ____ Date: _________________________

	Not at all	A little	Quite a bit	Very much
Have you been feeling self-conscious about your appearance?	....	....	....	....
Have you felt less physically attractive as a result of your disease or treatment?	....	....	....	....
Have you been dissatisfied with your appearance when dressed?	....	....	....	....
Have you been feeling less feminine/masculine as a result of your disease or treatment?	....	....	....	....
Did you find it difficult to look at yourself naked?	....	....	....	....
Have you been feeling less sexually attractive as a result of your disease or treatment?	....	....	....	....
Did you avoid people because of the way you felt about your appearance?	....	....	....	....
Have you been feeling the treatment has left your body less whole?	....	....	....	....
Have you felt dissatisfied with your body?	....	....	....	....
Have you been dissatisfied with the appearance of your scar?	....	....	....	....
	Not Applicable		....	

Dr P. Hopwood, CRC Psychological Medicine Group, Stanley House, Christie Hospital NHS Trust, Wilmslow Road, Withington, Manchester M20 4BX Tel.: 0161 446 3683 Fax: 0161 446 8103.

Appendix F. Short Form Health Survey 12.



SF-12 Health Survey

This survey asks for your views about your health. This information will help keep track of how you feel and how well you are able to do your usual activities. **Answer each question by choosing just one answer**. If you are unsure how to answer a question, please give the best answer you can.

1. **In general, would you say your health is**:

☐1 Excellent ☐2 Very good ☐3 Good ☐4 Fair ☐5 Poor

The following questions are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much?

	YES, limited a lot	**YES, limited a little**	**NO, not limited at all**
2. **Moderate activities** such as moving a table, pushing a vacuum cleaner, bowling, or playing golf.	☐1	☐2	☐3
3. Climbing **several** flights of stairs.	☐1	☐2	☐3

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of your physical health?

	YES	**NO**
4. **Accomplished less** than you would like.	☐1	☐2
5. Were limited in the **kind** of work or other activities.	☐1	☐2

During the past 4 weeks, have you had any of the following problems with your work or other regular daily activities as a result of any emotional problems (such as feeling depressed or anxious)?

	YES	**NO**
6. **Accomplished less** than you would like.	☐1	☐2
7. Did work or activities **less carefully than usual**.	☐1	☐2

8. **During the past 4 weeks, how much did pain interfere with your normal work (including work outside the home and housework)?**

☐1 Not at all ☐2 A little bit ☐3 Moderately ☐4 Quite a bit ☐5 Extremely

These questions are about how you have been feeling during the past 4 weeks.
For each question, please give the one answer that comes closest to the way you have been feeling.

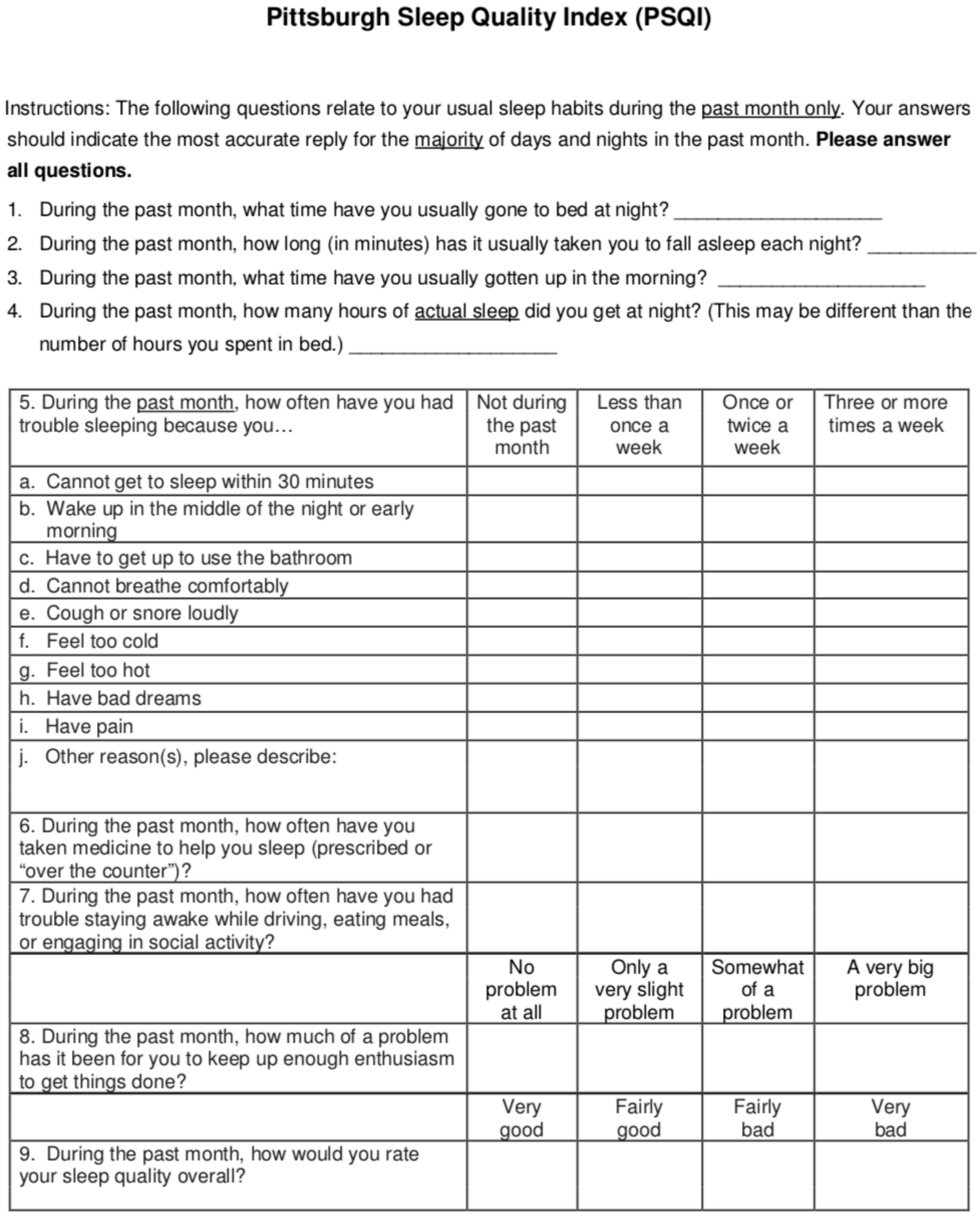
How much of the time during the past 4 weeks…

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
9. Have you felt calm & peaceful?	☐1	☐2	☐3	☐4	☐5	☐6
10. Did you have a lot of energy?	☐1	☐2	☐3	☐4	☐5	☐6
11. Have you felt down-hearted and blue?	☐1	☐2	☐3	☐4	☐5	☐6

12. **During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives, etc.)?**

☐1 All of the time ☐2 Most of the time ☐3 Some of the time ☐4 A little of the time ☐5 None of the time

Appendix G. Pittsburgh Sleep Quality Index.



Pittsburgh Sleep Quality Index (PSQI)

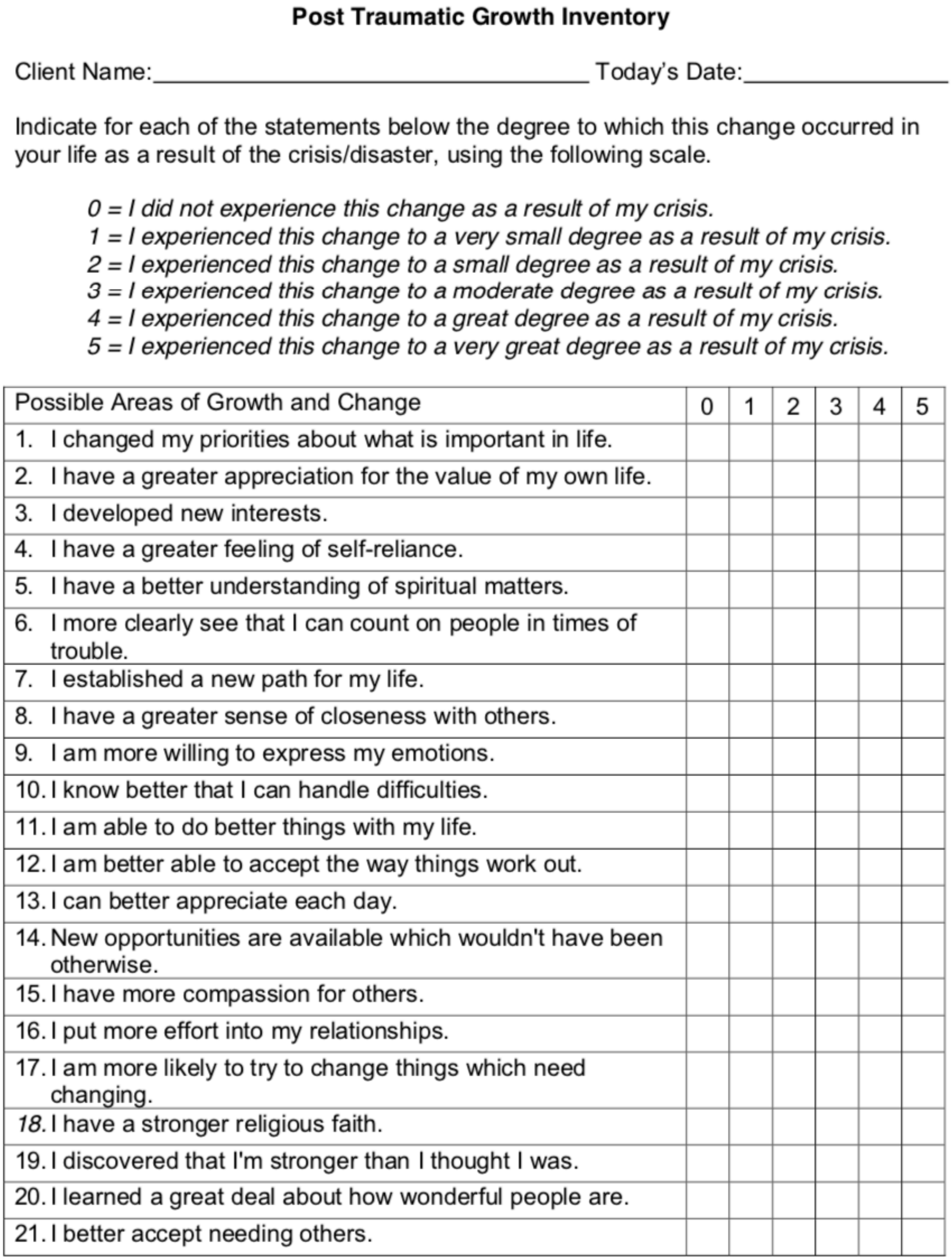
Instructions: The following questions relate to your usual sleep habits during the past month only. Your answers should indicate the most accurate reply for the majority of days and nights in the past month. **Please answer all questions.**

1. During the past month, what time have you usually gone to bed at night? ____________________
2. During the past month, how long (in minutes) has it usually taken you to fall asleep each night? __________
3. During the past month, what time have you usually gotten up in the morning? ____________________
4. During the past month, how many hours of actual sleep did you get at night? (This may be different than the number of hours you spent in bed.) ____________________

5. During the past month, how often have you had trouble sleeping because you…	Not during the past month	Less than once a week	Once or twice a week	Three or more times a week
a. Cannot get to sleep within 30 minutes				
b. Wake up in the middle of the night or early morning				
c. Have to get up to use the bathroom				
d. Cannot breathe comfortably				
e. Cough or snore loudly				
f. Feel too cold				
g. Feel too hot				
h. Have bad dreams				
i. Have pain				
j. Other reason(s), please describe:				
6. During the past month, how often have you taken medicine to help you sleep (prescribed or "over the counter")?				
7. During the past month, how often have you had trouble staying awake while driving, eating meals, or engaging in social activity?				
	No problem at all	Only a very slight problem	Somewhat of a problem	A very big problem
8. During the past month, how much of a problem has it been for you to keep up enough enthusiasm to get things done?				
	Very good	Fairly good	Fairly bad	Very bad
9. During the past month, how would you rate your sleep quality overall?				

	No bed partner or room mate	Partner/room mate in other room	Partner in same room but not same bed	Partner in same bed
10. Do you have a bed partner or room mate?				
	Not during the past month	Less than once a week	Once or twice a week	Three or more times a week
If you have a room mate or bed partner, ask him/her how often in the past month you have had:				
a. Loud snoring				
b. Long pauses between breaths while asleep				
c. Legs twitching or jerking while you sleep				
d. Episodes of disorientation or confusion during sleep				
e. Other restlessness while you sleep, please describe:				

Appendix H. Post Traumatic Growth Inventory.



Post Traumatic Growth Inventory

Client Name:________________________________ Today's Date:________________

Indicate for each of the statements below the degree to which this change occurred in your life as a result of the crisis/disaster, using the following scale.

0 = I did not experience this change as a result of my crisis.
1 = I experienced this change to a very small degree as a result of my crisis.
2 = I experienced this change to a small degree as a result of my crisis.
3 = I experienced this change to a moderate degree as a result of my crisis.
4 = I experienced this change to a great degree as a result of my crisis.
5 = I experienced this change to a very great degree as a result of my crisis.

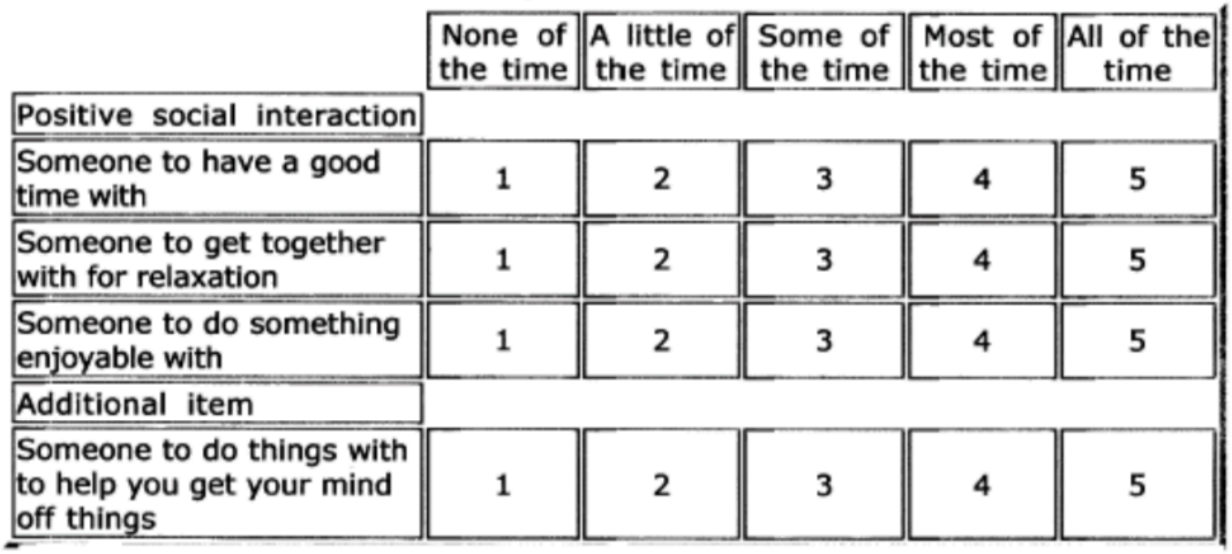
Possible Areas of Growth and Change	0	1	2	3	4	5
1. I changed my priorities about what is important in life.						
2. I have a greater appreciation for the value of my own life.						
3. I developed new interests.						
4. I have a greater feeling of self-reliance.						
5. I have a better understanding of spiritual matters.						
6. I more clearly see that I can count on people in times of trouble.						
7. I established a new path for my life.						
8. I have a greater sense of closeness with others.						
9. I am more willing to express my emotions.						
10. I know better that I can handle difficulties.						
11. I am able to do better things with my life.						
12. I am better able to accept the way things work out.						
13. I can better appreciate each day.						
14. New opportunities are available which wouldn't have been otherwise.						
15. I have more compassion for others.						
16. I put more effort into my relationships.						
17. I am more likely to try to change things which need changing.						
18. I have a stronger religious faith.						
19. I discovered that I'm stronger than I thought I was.						
20. I learned a great deal about how wonderful people are.						
21. I better accept needing others.						

Appendix I. Medical Outcome Survey – Social Support Survey.

MOS Social Support Survey

People sometimes look to others for companionship, assistance, or other types of support. How often is each of the following kinds of support available to you if you need it? Circle one number on each line.

	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Emotional/informational support					
Someone you can count on to listen to you when you need to talk	1	2	3	4	5
Someone to give you information to help you understand a situation	1	2	3	4	5
Someone to give you good advice about a crisis	1	2	3	4	5
Someone to confide in or talk to about yourself or your problems	1	2	3	4	5
Some whose advice you really want	1	2	3	4	5
Someone to share your most private worries and fears with	1	2	3	4	5
Someone to turn to for suggestions about how to deal with a personal problem	1	2	3	4	5
Someone who understands your problems	1	2	3	4	5
Tangible support					
Someone to help you if you were confined to bed	1	2	3	4	5
Someone to take you to the doctor if you needed it	1	2	3	4	5
Someone to prepare your meals if you were unable to do it yourself	1	2	3	4	5
Someone to help with daily chores if you were sick	1	2	3	4	5
Affectionate support					
Someone who shows you love and affection	1	2	3	4	5
Someone to love and make you feel wanted	1	2	3	4	5
Someone who hugs you	1	2	3	4	5



	None of the time	A little of the time	Some of the time	Most of the time	All of the time
Positive social interaction					
Someone to have a good time with	1	2	3	4	5
Someone to get together with for relaxation	1	2	3	4	5
Someone to do something enjoyable with	1	2	3	4	5
Additional item					
Someone to do things with to help you get your mind off things	1	2	3	4	5