The Experience of Parental Cancer Among Young Adult University Students and its Influence on Health Beliefs and Behaviours

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ABSTRACT

THE EXPERIENCE OF PARENTAL CANCER AMONG YOUNG ADULT UNIVERSITY STUDENTS AND ITS INFLUENCE ON HEALTH BELIEFS AND BEHAVIOURS

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Cancer is a disease that can have negative and some positive outcomes for the survivor, caregiver, and offspring. To date, there has been little research on the experiences of young adult offspring. When these offspring are also university students, they can experience unique challenges. This study aimed to explore the experience of parental cancer among young adult university students by interviewing 17 university students and using thematic analysis. Participants faced challenges with their friendships but found that the experience brought their family closer. Most participants gained an altered and more positive life outlook. Parental cancer caused distress and led to a decreased ability to focus at school but some participants found their experience to be a source of motivation. Participants became more health conscious, made lifestyle changes and felt they were more susceptible to cancer. The university atmosphere, time, and money were identified as barriers to making lifestyle changes.

Keywords
behavior change, cancer, health and well-being, interviews, semi-structured, lived experience, self-efficacy, research, qualitative, social constructionism, young adults
Dedication

I would like to dedicate this thesis to my late father, Michael R. McPhail, who passed away from cancer in January 2012. Your love, advice, and values have continually shaped me and I will always miss you and love you.
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1.0 Introduction

In this thesis we will examine the literature on cancer and the cancer experience for survivors, patients, caregivers, and the family and offspring. The literature review will be followed by the rationale for examining young adult university students, the methods of the study, the results of the study, and the discussion section.

Canadians have a 2 in 5 chance of developing cancer at some point in their lifetime (Canadian Cancer Society’s Advisory Committee on Cancer Statistics, 2014). It is estimated that in 2014 there will be 191,300 new cases of cancer and 76,600 people will die from cancer (Canadian Cancer Society’s Advisory Committee on Cancer Statistics, 2014). Although 5-10% of cancer types occur in relation to genetic disposition, 90-95% of cancers occur due to lifestyle factors (Anand et al., 2008). The five leading behavioural and dietary risks for developing cancer are: tobacco use, alcohol use, overweight and obesity, physical inactivity and low fruit and vegetable intake (World Health Organization, 2013). For those with cancer, behavioural risk factors can influence complications from treatment, likelihood of cancer recurrence post-treatment, quality of life, subsequent primary cancer incidence, and the incidence of other chronic diseases such as cardiovascular disease and diabetes (Coups & Ostroff, 2005). Cancer survivors are not currently meeting guidelines for physical activity, nutrition, or weight status (Coups & Ostroff, 2005; Courneya, Katzmarzyk, & Bacon, 2008). Unfortunately, cancer survivors face a number of unique physical and psychosocial challenges post-treatment that can influence their physical activity levels, eating habits, stress management, and overall well-being (Howell et al., 2012).
Research around the cancer experience has mostly focused on the dysfunction and challenges that occur but there is also considerable research suggesting that a large percentage of cancer survivors can adjust well and experience psychological growth after receiving a cancer diagnosis (Bellizzi, 2004; Thornton, 2002). Cancer is a disease that not only affects the person with cancer but also the family members, friends, and co-workers of that individual (Kim & Given, 2008). Caregivers can also experience post-traumatic growth from their caregiving experience because they are heavily involved in the cancer experience itself (Thornton & Perez, 2006). Caregivers can experience positive outcomes from their caregiving experience such as: control over their own life, appreciating others, finding life meaning, and changing attitudes and values in their life (Kang et al., 2013).

The offspring of a person with cancer have to view the emotional and physical suffering of their parent and prepare for the possible loss of that parent and this can be a traumatic experience regardless of the type of cancer (Mosher & Danoff-Burg, 2005). The experience of parental cancer during young adulthood is unexpected and incongruent with social expectations of when someone has to face the life-threatening illness of a parent and the possible death of that parent (Puterman & Cadell, 2008). Although traumatic, the experience of parental cancer may influence the adult offspring in becoming more aware of his or her personal cancer risk and also his or her own inevitable mortality (Mosher & Danoff-Burg, 2005). Young adults who are students and are dealing with a parent’s illness are also expected to confront issues in adjustment to university or college because of the separation from their families and their increased independence (Schmidt & Welsh, 2010).

The experience of parental cancer can potentially lead to the offspring changing the relationship with their sick parent, understanding the importance of family, altering their life
priorities, and participating in personal development (Levesque & Maybery, 2012). Personal development may include having an increased awareness of personal risk of cancer and preventive measures that can be taken to reduce that risk (Levesque & Maybery, 2012).

Research has also focused on the experiences of children and adolescents who have had a parent with cancer even though the majority of cancer patients’ children are actually adults (Levesque & Maybery, 2012). More research is needed examining the positive outcomes of having a parent with cancer, especially the experiences of young adults (Levesque & Maybery, 2012). There has also been little research examining young adults who are attending a post-secondary institution and who have experienced their parent having cancer (Schmidt & Welsh, 2010).
2.0 Literature Review

2.1 Cancer Prevalence

In 2008, cancer accounted for the deaths of 7.6 million people, which is 13% of all deaths (IARC, 2008). The types of cancer that caused the most deaths worldwide were lung (1.37 million), stomach (736,000), liver (695,000), colorectal (608,000), and breast cancer (458,000) (IARC, 2008). Canada uses a cancer registry system that allows for the observation of cancer trends (Canadian Cancer Society’s Steering Committee on Cancer Statistics, 2012). The registries that are used are The Canadian Cancer Registry (CCR), National Cancer Incidence Reporting System (NCIRS), and Canadian Vital Statistics: Death Database (CVS: D). Canadians have a 2 in 5 chance of developing cancer at some point in their lifetime (Canadian Cancer Society’s Advisory Committee on Cancer Statistics, 2014). It is estimated that in 2014 there will be 191,300 new cases of cancer and 76,600 people will die from cancer (Canadian Cancer Society’s Advisory Committee on Cancer Statistics, 2014). The highest rates of cancer for men and women occur in the Atlantic Provinces, Quebec and Ontario and the lowest rates of all cancers occur in British Columbia (Canadian Cancer Society’s Steering Committee on Cancer Statistics, 2012).

Lung cancer is connected to 27% of all cancer deaths in Canada. Half of all new cancer diagnoses will be lung, colorectal, prostate and breast cancers. Prostate cancer is the most common cancer in men and breast cancer is the most common cancer in women. Sixty-nine percent of new cases and 62% of deaths will be women and men between the ages of 50 and 79 years. Cancer is more common in men except between the ages 20 and 50 when women have a higher incidence of cancer (Canadian Cancer Society’s Steering Committee on Cancer Statistics, 2012).
2.2 Lifestyle-related Risk Factors

Although 5-10% of cancer types are considered genetic, 90-95% of cancers occur due to a combination of environmental and lifestyle factors (Anand et al., 2008). The five leading behavioural and dietary risks for developing cancer are: tobacco use, alcohol use, overweight and obesity, physical inactivity, and low fruit and vegetable intake (World Health Organization, 2013). High exposure to UV radiation through sun exposure is also a behavioural risk factor (Murphy & Miller, 2008). In this section, the various lifestyle-related risk factors in detail will be described.

2.2.1 Tobacco Use

The relationship between tobacco use and cancer risk, specifically lung cancer, was established in Britain and North America in the 1950s and has since continued to be studied for its role in all cancer types (Murphy & Miller, 2008). The Canadian Cancer Society (2013) has identified quitting smoking and/or living smoke-free as the number one ways that a person can reduce his or her risk of developing cancer.

Tobacco use contributes to 22% of cancer deaths worldwide as well as 71% of lung cancer incidences (World Health Organization, 2013). Tobacco smoke has also been linked to increasing the risk of developing at least 14 types of cancer (Irigaray et al., 2007). In 1964, the US Surgeon General’s Advisory Commission Report identified smoking as the primary cause of lung cancer, although the mechanism for which tobacco smoke can cause cancer is not completely understood (Anand et al., 2008). Cigarettes contain 4,000 chemicals and poisons and 70 of them are known to be carcinogenic (Canadian Cancer Society, 2013).

2.2.2 Alcohol Consumption

Alcohol consumption has been linked predominantly to the development of cancers of the
upper aero-digestive tract, including cancers of the oral cavity, larynx, pharynx, hypopharynx, and oesophagus (Anand et al., 2008; Seitz, Stickel, & Homann, 2004). Alcohol consumption is also linked to the incidence of cancers of the liver, breast, pancreas, colon and rectum (Anand et al., 2008; Canadian Cancer Society, 2013).

Alcohol’s contribution to cancer risk is not well understood but it is thought that ethanol may play a co-carcinogenic role (Anand et al., 2008; Irigaray et al., 2007). Alcohol itself is not considered to be a carcinogen on its own but as ethanol is digested, free radicals and acetaldehyde are formed and these compounds are responsible for alcohol’s carcinogenic effects (Anand et al., 2008). There is also an interaction between smoking and alcohol consumption, which can increase a person’s risk for cancers of the oral cavity, pharynx, larynx, and oesophagus (Murphy & Miller, 2008). Complete avoidance of alcoholic drinks can be justified because there is no threshold level of alcohol consumption for which there is no increased risk for cancer (Miles, 2008)

2.2.3 Overweight and Obesity

The evidence showing that overweight and obesity are major risk factors for cancer development has become stronger (Miles, 2008). The report Food, Nutrition, Physical Activity and the Prevention of Cancer: A Global Perspective, presented by The World Cancer Research Fund (WCRF) and the American Institute for Cancer Research (AICR) in 2007, suggests that there is a relationship between individuals’ body fatness and their cancer risk (Miles, 2008). This means that among persons with a normal Body Mass Index (BMI) between 18.5 and 24.9, those who have more lean body mass tend to have a lower risk of cancer (Miles, 2008).

Overweight and obesity are associated with increased risk for cancers of the breast in post-menopausal women, colon, endometrium, kidneys, oesophagus, gastric cardiac, pancreas,
gallbladder, liver, and prostate (Calle, Rodriguez, Walker-Thurmond, & Thun, 2003; Miles, 2008). The relationship between obesity and cancer has been related to insulin resistance, insulin like growth factor and insulin, sex steroids and overall immune function (IARC, 2002). The storage of carcinogens in adipose tissue may also play a role in the relationship between overweight and obesity and cancer (Friedenreich, 2001)

2.2.4 Physical Activity

Physical activity has become widely known to be protective against cardiovascular diseases such as stroke, hypertension and coronary heart disease, as well a type 2 diabetes and osteoarthritis (Murphy & Miller, 2008). Physical activity is now also considered to be one of the most important modifiable risk factors in cancer prevention (Miles, 2008). The evidence supporting the relationship between regular physical activity and the reduced occurrence of various cancers is extensive as is the evidence supporting that a sedentary lifestyle is associated with other illnesses such as type 2 diabetes and heart disease (Anand et al., 2008).

The current physical activity recommendations in Canada are that adults between the ages of 18 and 64 should accumulate 150 minutes of moderate to vigorous aerobic activity per week in bouts of 10 minutes or more (Canadian Society for Exercise Physiology, 2012). Moderate activities include activities such as brisk walking and bike riding and vigorous activities include activities such as jogging and cross-country skiing (Canadian Society for Exercise Physiology, 2012).

Physical activity can be a means of protection against weight gain and weight-related cancers but there is also evidence showing that physical activity alone reduces a person’s risk of specific cancers (Miles, 2008). Physical activity plays a role in risk reduction of colorectal cancer, breast cancer and endometrial cancer (Claque & Bernstein, 2012; Friedenreich, 2001;
Miles, 2008). The mechanisms involved between cancer risk and physical activity levels need to be explored further but Friedenreich (2001) has proposed the following mechanisms. Physical activity can increase gut motility and decrease the amount of time that the body is exposed to potential carcinogens thus reducing the risk of colorectal cancers. Physical activity also plays a role in the reduced risk of breast cancer by reducing estrogen production and bioavailability. Prostate cancer risk is reduced with physical activity as well because of the lower levels of the male sex hormone, testosterone.

### 2.2.5 Nutrition

Health Canada is responsible for issuing dietary guidelines, such as *Eating Well with Canada’s Food Guide (EWCFG).* The recommendations for women between the ages of 19 and 50 years are 7-8 servings of fruits and vegetables, 6-7 servings of grains, 2 servings of dairy/alternatives, and 2 servings of meat/alternatives. Men of the same ages require 8-10 servings of fruits and vegetables, 8 servings of grains, 2 servings of dairy/alternatives and 3 servings of meat/alternatives (Health Canada, 2011).

#### 2.2.5.1 Convenience foods

The WCRF indicates that sugary, high-fat, calorie-dense, convenience foods may increase a person’s risk of gaining weight, thus increasing the overall risk of cancer and risk of cancer recurrence in survivors and reducing the likelihood of survival for current cancer patients (Courneya et al., 2007; Miles, 2008). Sugary drinks may also play a role because they don’t lead to satiety despite their caloric contents (Miles, 2008).

#### 2.2.5.2 Vegetable and Fruit Consumption

Fruits and vegetables provide vitamins, minerals and phytochemicals; they are high in fibre, and they are low in fat and calories (Canadian Cancer Society, 2013). Fruits and
vegetables are also a high source of the antioxidants and current recommendations suggest that people consume antioxidants through food sources rather than through supplementation (Courneya et al., 2007). The features of fruits and vegetables make their consumption an important part of a healthful, balanced diet (Health Canada, 2011).

Non-starchy vegetables have been shown to reduce the risk of cancers of the mouth, pharynx, larynx, oesophagus, and stomach (Miles, 2008). Specifically, fruit consumption has been associated with reduced risk for cancers of the mouth, larynx, pharynx, oesophagus, lung and stomach (Miles, 2008). The relationship between fruit and vegetable intake and cancer risk reduction is unclear but in the WCRF/AICR report, *Food, Nutrition, Physical Activity and the Prevention of Cancer: A Global Perspective*, the correlations between fruit and vegetable consumption and overall cancer risk were labeled as “probable” or “limited-suggestive” while some other lifestyle factors had the higher overall rating of “convincing evidence” (Murphy & Miller, 2008).

### 2.2.5.3 Red Meat and Processed Meats

Consumption of red meats and processed meats increases an individual’s risk of developing colorectal cancer (Canadian Cancer Society, 2013). Red meat and processed meats are both high in saturated fats and high consumption of these products can lead to higher caloric intake, which in turn can affect a person’s ability to maintain a healthy weight. Red meat includes beef, lamb, goat and pork and processed meats include ham, salami, bacon, hot dogs and sausages. The processing methods that occur are smoking, curing, salting, and the addition of preservatives.

In the WCRF/AICR report, *Food, Nutrition, Physical Activity and the Prevention of Cancer: A Global Perspective*, there was strong evidence that the consumption of red meat
increases the risk of colorectal cancer and that processed meats lead to greater overall risk (Miles, 2008). The consumption processed meats involves an increased consumption of saturated fats, sodium, and calories that could lead to potential weight gain, which is also a risk factor for cancer (Canadian Cancer Society, 2013; Miles, 2008).

2.2.6 Sun Exposure

The sunlight in Canada is strong enough to cause skin cancer and the risk of someone developing skin cancer today is higher than it was 20 years ago (Canadian Cancer Society, 2013). Ultraviolet (UV) rays from natural sunlight, sunbeds, and cosmetic tanning are considered to be carcinogenic as they cause a form of nonionizing radiation (Anand et al., 2008). UV radiation is a risk factor for basal cell carcinoma, squamous cell carcinoma, and melanoma (Anand et al., 2008). The two types of UV rays that can reach the earth’s surface are Ultraviolet A (UVA) and B (UVB) rays (Canadian Cancer Society, 2013). UVA rays make up the majority of the sun’s light but UVB rays are the primary cause of sunburns because they are nearly 1000 times stronger than UVA rays (Canadian Cancer Society, 2013). The Canadian Cancer Society (2013) states that individuals who are exposed to sunlight for lengthy periods of time, have fair coloured skin, hair and eyes are at a higher risk of developing skin cancer. People who are more sensitive to UV light because of medication, and experienced blistering sunburns as a child are also at a higher risk of developing skin cancer.

2.3 Cancer Survivor Health

The current knowledge about early cancer detection and the ability to provide effective treatment have allowed some people with cancer to recover with the expectation that they will live for decades longer than those who developed cancer previously (Bellizzi, Rowland, Jeffery & McNeel, 2005). According to the report Canadian Cancer Statistics 2012, put forth by the
Canadian Cancer Society’s Steering Committee on Cancer Statistics (2012), survival rates have increased from 56% to 62% from the period 1992-1994 to 2004-2006. Cancer survival percentage is defined as the percentage of people diagnosed with cancer who live for 5 or more years after their cancer diagnosis.

With a growing number of cancer survivors, there has been an increased emphasis on behavioural risk factors and their role in cancer morbidity and mortality (Coups & Ostroff, 2005). Behavioural risk factors can influence complications from treatment, likelihood of cancer recurrence post-treatment, quality of life, subsequent primary cancer incidence, and the incidence of other chronic diseases such as cardiovascular disease and diabetes (Coups & Ostroff, 2005). Cancer survivors should aim to have an appropriate weight, become more physically active and consume a healthful diet to improve long-term outcomes and prevent cancer recurrence and the development of secondary cancers (Doyle et al., 2006). Cancer survivors may be concerned about the chances of cancer recurrence and so their outlook on life changes and they begin to lead a healthier lifestyle (Bower et al., 2005).

There are health and lifestyle recommendations available to cancer survivors; however, many cancer survivors may not be aware of their existence (Bellizzi et al., 2005). Oncologists can play an important role in providing support and guidance as well as giving recommendations based on each individual’s health status and functional ability. Unfortunately, cancer survivors face a number of unique physical and psychosocial challenges post-treatment that can influence their physical activity levels, eating habits, stress management, and overall well-being (Howell et al., 2012). In a study examining National Health Interview Survey (NHIS) data from 2000, which compared cancer survivors with those who had no history of cancer, it was found that the following behavioural risk factors were highly prevalent among those with a history of cancer as
well as those who had never had cancer: physical inactivity, low fruit and vegetable intake, high fat diets, low fibre intake, being overweight, risky alcohol use and lack of sun protection behaviours (Coups & Ostroff, 2005). The following section will address the challenges associated with physical activity, nutritional factors, and weight status amongst cancer survivors.

2.3.1 Physical Activity and Its Challenges

In a study that examined data from the 2005 Canadian Community Health Survey, fewer than 22% of cancer survivors reported being active, with female and male colorectal, female breast cancer, and melanoma skin cancer survivors reporting the lowest rates of physical activity (Courneya et al., 2007). Analysis of data collected from NHIS in the United States suggests that cancer survivors between the ages of 18 and 40 years of age were more likely to meet physical activity recommendations than survivors between the ages of 40 and 64 years of age and survivors more than 64 years of age (Bellizzi et al., 2005). Prostate cancer and skin cancer survivors tend to be the most active, in general (Courneya et al., 2007).

It’s important to note that physical activity may not be feasible for some cancer survivors due to the physical and psychosocial challenges that they may face (Howell et al., 2012). It has also been shown that cancer survivors have a tendency of becoming more sedentary following a cancer diagnosis and that they rarely return to pre-cancer activity levels (Irwin et al., 2003). This sedentary behaviour is likely caused by the adverse effects of some cancer therapies, which can affect the cardiopulmonary, muscular and neurologic systems (Doyle et al., 2006). In some cancer survivors, the combination of a pre-existing sedentary lifestyle leading to poor stamina and strength with the combination of managing the stress of a cancer diagnosis and its associated treatments and recovery period can make increasing physical activity more of a challenge (Doyle et al., 2006). However, when examining physical activity intervention programs that gradually
increase cancer survivors’ moderate and vigorous physical activity levels, participants have reduced anxiety and depression, less fatigue and an increase in self-esteem and overall mood (Courneya, 2003). For those cancer survivors who are considered to be physically active, there were certain motivational factors that lead them to the behaviour change (Satia, Walsh, & Pruthi, 2009). Cancer survivors’ motivating reasons included wanting to avoid future disease, maintain their current level of health, manage their weight, and recuperate and regain their former vitality.

In summary, the prevalence of low physical activity levels among cancer survivors is similar to that of the general population in Canada (Courneya et al. 2007). Cancer survivors and those with no cancer history are not meeting physical activity recommendations and cancer diagnoses don’t seem to influence health behaviour changes.

2.3.2 Nutritional Factors

In the study examining NHIS data from 2000, comparing cancer survivors with those who had no history of cancer, fruit and vegetable intake, low fat diet, and high fibre diet were assessed (Coups & Ostroff, 2005). The prevalence of the behaviours was age stratified and did not differ greatly between the two samples. Approximately 50% of participants consumed less than 5 fruit and vegetable servings a day. Greater than 70% of individuals, ages 18-64, consumed a diet that was more than 30% fat but only 50-52% of those more than 65 years of age consumed a diet that was greater than 30% fat. Approximately 84-92% of all participants consumed less than 25 grams of fibre per day.

2.3.3 Weight Status

About 1/5th of Canadian cancer survivors are estimated to be obese, which puts them at higher risk for poor disease and supportive care outcomes (Courneya et al., 2007). Compared to non-cancer controls, cancer survivors have a similar prevalence of overweight status, with those
ages 40-64 having the highest prevalence of overweight (Coups & Ostroff, 2005).

For some cancer survivors, further weight loss can be a problem due to intensive cancer treatments (Doyle et al., 2006). Dietary intake and energy expenditure should be assessed because further weight loss can interfere with the survivor’s quality of life, the completion of his or her cancer treatment, and the process of healing. However, many cancer survivors are overweight or obese when they are diagnosed with cancer and this has been shown to increase the risk of cancer recurrence and reduce the likelihood of survival for certain types of cancer (Coups & Ostroff, 2005; Doyle et al., 2006). Healthy weight loss should be achieved through a balanced diet and increased physical activity (Doyle et al., 2006).

2.4 Cancer Survivor Experience

The cancer experience is unique because cancer is a disease that can occur without warning and may be difficult to diagnose (Thornton, 2002). Cancer has various forms, levels of severity, and an etiology and development system that are not well understood and this can affect the current and future well-being of the person diagnosed (Thornton, 2002). Research around the cancer experience has mostly focused on the dysfunction and challenges that occur but there is also considerable research suggesting that a large percentage of cancer survivors can adjust well and experience psychological growth after receiving a cancer diagnosis (Bellizzi, 2004; Thornton, 2002). Some studies suggest that the psychosocial impact of the cancer experience can have a stronger effect in younger cancer survivors than it does in older cancer survivors in the areas of diet, exercise, and spiritual activities (Ganz et al., 2002). Research has also been more focused on the psychological effects of the diagnosis period, the treatment period and cancer recurrence but there has been less focus on the period of survivorship (Tomich & Helgeson, 2002).
For years after treatment, cancer survivors can continue to feel that their life has been altered in a significant way (Thornton, 2002). Cancer survivors experience a significant impact on their lives by becoming aware of the fragility of life and their own mortality (Bellizzi, 2004). Survivors can also experience distress because of the uncertainty of their own future and the uncertainty of their personal health status (Preyde, Chevalier, Hatton-Bauer, & Barksey, 2010). Cancer survivors can perceive changes in their lives through finding meaning and their own vulnerability (Giedzinska, Meyerowitz, Ganz & Rowland, 2004). Feelings of vulnerability may be experienced after a cancer diagnosis because there is a realization that loss can occur at any time and this motivates individuals to make positive changes in their outlook of life and in their priorities (Bower et al., 2005). However, feelings of vulnerability that involve cancer are related to poor adjustment and negative effects on a person’s mental health (Bower et al., 2005). Meaning seeking post-recovery has also been associated with poorer mental functioning and decreased quality of life but finding a purpose in life has been positively associated with improved quality of life (Tomich & Helgeson, 2002). When the cancer experience is perceived as being harmful, physical and mental functioning may suffer but if the experience is deemed beneficial, quality of life can improve (Tomich & Helgeson, 2002). Cancer survivors don’t often change their views on how good and just the world is but after their experience with a cancer diagnosis, there is a tendency to view the world as more random and less predictable (Tomich & Helgeson, 2002).

More often than not, the changes that cancer survivors experience lead to a more positive life perspective with altered priorities, investment in their relationships, and positive changes within themselves (Thornton, 2002). This experience may also lead a cancer survivor to develop higher levels of psychological functioning, life awareness and adaptation (Bellizzi, 2004).
Feelings of personal control in life as well as feelings that one is lucky are associated with increased mental functioning and improved quality of life in the cancer survivor experience (Tomich & Helgeson, 2002). One longitudinal study examining breast cancer survivors found that the positive benefits of having the experience of cancer included an improved ability to relate to others, find new possibilities, experience personal strength/growth, experience spirituality, and have a deeper appreciation of life (Sears, Stanton, & Danoff-Burg, 2003). Research has found that in order for survivors to improve adjustment and quality of life, they must also seek out strong social support (Ganz et al., 2002).

The experience of being diagnosed with cancer and then recovering from it can be a form of post-traumatic growth if the person perceives positive changes after having experienced the crisis (Tedeschi & Calhoun, 1996). Park, Chmielewski, & Blank (2010) found that in a sample of young adults who had survived cancer, those who perceived more positive growth from their cancer experience, experienced less thought “intrusions”, or uncontrollable thoughts, images, and feelings relating to a negative or stressful life experience. The intrusive thoughts that still occurred affected the young adults less negatively and actually improved their well-being rather than hindering it if they had experienced more post-traumatic growth.

“Benefit finding” or perceiving positive outcomes from an experience, earlier on in the cancer experience, can also predict improved quality of life in cancer survivorship (Carver & Antoni, 2004). The process of benefit finding also appears to be independent of both medical and demographic characteristics, for example, disease stage or household income (Thornton, 2002). A longitudinal study examining breast cancer survivors found that intensive perceived stress to cancer followed by time to process this experience was related to increased post-traumatic growth a year later (Sears et al., 2003). Also, education and optimism predicted
benefit finding in the form of positive outcome expectancies while hope and reappraising the cancer experience in a positive light reflect active intention to pursue positive outcomes (Sears et al., 2003). Optimism has also been associated with decreased levels of depression and better physical functioning among cancer survivors (Tallman, Altmaier, & Garcia, 2007).

2.5 Caregiving

Cancer is a disease that not only affects the person with cancer but also the family members, friends, and co-workers of that individual (Kim & Given, 2008). Caregiving for a family member means that some caregivers may play a primary role in the cancer patient’s symptom management, monitoring of treatment and disease progression, methods of transportation, and maintenance of medical equipment such as an IV (Given, Given & Kozachik, 2001). The caregiver plays an important supportive role by aiding in personal care and providing emotional, financial, and spiritual support (Given et al., 2001). The caregiver may become responsible for certain former responsibilities that the cancer patient can no longer maintain due to his/her illness and it is common for caregivers to suffer from anxiety and/or depression during the caregiving experience (Given et al., 2001). This section will describe the challenges different types of caregivers face and how this influences their quality of life, how the caregiving experience affects caregivers’ health behaviours, the role of support systems in the caregiving experience, and the positive outcomes caregivers experience.

A caregiver’s quality of life is affected by mental, social, spiritual, physical, and behavioral factors that exist during the caregiving period and through all stages of his/her loved one’s illness (Kim & Given, 2008). Funk et al. (2010) conducted a review of the literature on caregiving at the end of life, which included caregiving of cancer patients. It was found that providing end-of-life care lead to caregivers experiencing decreases in their own physical health,
isolation from social activities and friends, changes in lifestyle, disruptions to regular routine, time management issues, financial issues, and employment issues. The research examining whether family members are influenced to make their own lifestyle changes, such as eating healthier or becoming more physically active, after observing a family member experience cancer has been minimal (Kim & Given, 2008). Mazanec, Daly, Douglas, and Lipson (2011) explored the health behaviour practices and work productivity of caregivers of people with an advanced form of cancer. Caregivers rated their personal health as “good” or “excellent” and they reported participating in screening, regular medical appointments, and having a healthy diet. The caregivers didn’t report meeting the recommendation of 150 minutes of moderate physical activity per week (Canadian Society for Exercise Physiology, 2012; Mazanec, Daly, Douglas, & Lipson, 2011). During the caregiving period, participants had an average decrease in work productivity of 22.9% (Mazanec, Daly, Douglas, & Lipson, 2011). The factors that were related to decreased work productivity were depression, anxiety, caregiving burden, financial issues, and personal health problems (Mazanec, Daly, Douglas, & Lipson, 2011). Low personal physical health ratings were related to lower physical activity levels and decreased work productivity (Mazanec, Daly, Douglas, & Lipson, 2011).

The findings by Funk et al. (2010) and Mazanec, Daly, Douglas, and Lipson (2011) point to caregivers being underprepared for their role, leading to powerful negative emotions, stress, and anxiety. The stress of caregiving was found to be due to a combination of realizing the impending loss of a loved one and seeing them suffer while also not having the support or information to provide proper care (Funk et al., 2010). In a study by Kim, Spillers and Hall (2012) in the United States, 5-year follow-up data were collected from the Nationwide Quality of Life Survey for Caregivers and this data showed how different caregiving experiences affected
the quality of life of caregivers. Caregiving experiences were assessed 2 years after the caregivers’ relatives received their cancer diagnosis and then quality of life components for the caregivers, such as mental health, physical health, psychosocial adjustment and spirituality, were assessed 5 years after their relatives received their cancer diagnosis. Caregivers were then classified as being former caregivers whose relative was in remission, former caregivers whose relative was deceased, and caregivers who were currently providing care. Older caregivers and those who had perceived the caregiving experience as less overwhelming had better mental functioning, but younger caregivers had higher physical functioning across all caregiver types. Psychological distress was associated with younger age and higher levels of caregiving stress. At 5 years post diagnosis, former caregivers whose relatives were in remission had normal levels of psychological well-being, while former caregivers who had lost their relative showed psychological distress and difficulty in spiritual adjustment. Current caregivers that were heavily involved in the care of a long-term surviving relative suffered from the lowest quality of life of all the groups of caregivers. Similarly, in another study by Kang et al. (2013), it was discovered that if the caregiver, regardless of gender, was caring for a spouse, it was more likely that those caregivers had more of a struggle experiencing personal and positive growth from the experience.

If there is a balance in support from other family members, friends, and medical professionals, then caregivers will have an increased capacity for their caregiving responsibilities, while minimizing their personal distress (Given et al., 2001). This balance allows caregivers to improve their psychological, physical, and emotional well-being and reduce levels of stress and depression, which can lead to the caregiver providing better care (Given et al., 2001). If caregivers can understand the value of the care they provide, this can also reduce
the burden of caregiving (Given et al., 2001). Health care professionals can play an important role by providing caregivers with information on how to care for their family member at home, thus easing a component of the frustration and stress of caregiving (Given et al., 2001). The health care professional can also tailor the care plan to fit both the needs of the patient and the caregiver (Given et al., 2001). Funk et al. (2010) concluded from their review of caregiving at the end of life that the majority of studies identified a need for balance between formal support, such as the healthcare team, and informal support from friends and family. These support systems can promote “coping”, “security”, “reassurance”, and the “manageability” of the experience itself (Funk et al., 2010).

The caregiving experience can also have positive components, such as when caregivers discover positive or rewarding aspects of their experience (Funk et al., 2010). These positive and/or rewarding aspects have been found to be a method of coping because it helps the caregiver find personal meaning in their caregiving role (Funk et al., 2010). Caregivers can also experience post-traumatic growth from their caregiving experience because they are heavily involved in the cancer experience itself (Thornton & Perez, 2006).

Kang et al. (2013) conducted a nationwide survey to determine what the positive outcomes of caregiving for a terminal cancer patient were. Older age, being female, being a spouse, and the caregiver’s religion significantly correlated with the positive outcomes of the caregiving experience. Older caregivers experienced more meaning in their life and they also reported appreciating others in their life more after their caregiving experience. Men benefit less from the caregiving experience than women do, but if a caregiver was female, she was more likely to experience mental health issues alongside experiencing the positive outcomes of caregiving. It’s also important to note that the investigators found that the caregivers’ depression
and/or experience of caregiving burden did not influence whether they perceived positive outcomes from the caregiving experience.

Religious beliefs were also found to increases the chances that caregivers would perceive positive outcomes from their experience. Kang et al. (2013) indicated that the most important finding of the study was that the care the caregiver received after the death of the cancer patient significantly increased the chance that caregivers could achieve positive outcomes from their experience such as: control over their own life, appreciating others, finding life meaning, and changing attitudes and values in their life. In the review of studies examining the caregiving experience at the end of life, it was found that there is little research examining how caregivers “make meaning” from their experience and how social ideals and norms affect how caregivers’ “make meaning” of their experience (Funk et al., 2010).

2.6 Family and Offspring

Examining the young adult experience of having a parent with cancer is important because the offspring of a cancer patient, like spousal caregivers, may have the ability to influence that cancer patient’s quality of life and even survival (Mosher & Danoff-Burg, 2005). The offspring of a person with cancer may view the emotional and physical suffering of their parent and prepare for the possible loss of that parent and this can be a traumatic experience regardless of the type of cancer (Mosher & Danoff-Burg, 2005). Although traumatic, the experience of parental cancer may influence the adult offspring in becoming more aware of his or her personal cancer risk and also his or her own inevitable mortality (Mosher & Danoff-Burg, 2005). Cancer patients’ spouses can experience personal growth from being involved in the cancer experience and so can their offspring (Patterson & Rangganadhan, 2010). This section will describe coping strategies, support systems, the influence of parental cancer on friendships,
relationships, and family, the influence severe illnesses have on students’ adjustment to university life, and the positive outcomes that some people have after experiencing a severe illness or parental cancer in particular.

One study examined how people perceive parental cancer and the types of coping strategies that they use, through structured interviews, where responses were made using a 4-point Likert scale (Compas, Worsham, Ey, & Howell, 1996). The study had 134 participants who were preadolescents, adolescents, and young adults who had a parent with cancer. The representation of males and females was approximately equal in each age group and participants were between the ages of 6 and 32 years. The findings suggest that participants use emotion-focused coping by avoiding or attempting to be distracted from their parent’s cancer or the feelings they were experiencing because of their parent’s cancer. Puterman and Cadell (2008) conducted a qualitative study examining the experiences of young adult women, ages 20 to 32 years, who were presently experiencing parental cancer. The participants were not bereaved but their parents had to have been diagnosed with cancer or suffered a relapse while the participants were young adults. Participants’ parents were receiving cancer treatment during the time of the study. These participants mentioned the need to “be present” and one participant discussed trying to avoid thinking too far into the future. Comparatively, in another study by Patterson and Rangganadhan (2010), adolescent and young adult participants identified their needs that were not met during their experience of losing a parent to cancer. The second most unmet need was “help coping with feelings” and participants acknowledged their need for assistance in managing their negative emotions such as feelings of anger, grief, and depression. It’s important to note that Compas et al. (1996) found that the emotion-focused coping strategies used to distract the offspring from their parent’s cancer were related to increased anxiety and depression in the
offspring. This type of coping also seemed to increase with age so that older participants were actually using less effective coping strategies than their younger counterparts.

As well as emotion-focussed coping, Compas et al. (1996) also found that participants used problem-focused coping. Participants coped by doing chores or other activities that would give their parent the chance to rest as a way of indirectly addressing their parents’ cancer. The participants’ responses related to information seeking about the type of cancer their parent had, through discussing it with their parent’s doctor or reading about it on their own. Patterson and Rangganadhan (2010) also found that participants expressed a need for more information on what treatment(s) their respective parent was undergoing, and specifically what the situation was for their parent.

Patterson and Rangganadhan (2010) also found that their participants, who were adolescents and young adults, had issues regarding support. These participants identified “support and understanding” as their most prevalent unmet need. The participants mentioned needing more support from their teachers, friends, the general public, and also their own family members. Friends were identified as being unable to have a full understanding of the experience of losing a parent to cancer and how this experience affected the bereaved adolescent or young adult. Conversely, participants identified the need “to talk to people who have had a similar experience” and that this could occur by communicating with other people their age, who had also lost a parent to cancer. Leedham and Meyerowitz (1999) examined the experiences of adult women who had lost a parent to cancer, and found that these women also recollected having difficulties with their relationships and friendships, while they were experiencing parental cancer. Schmidt and Welsh (2010) explored how facing the chronic and/or terminal illness of a family member affects university students’ adjustment to university life. Many students
identified withdrawing from social activities and feeling strain because there wasn’t enough time to spend with family and friends due to their family members’ illness.

Leedham and Meyerowitz (1999) found that their participants, the female adult offspring who experienced parental cancer in their youth, had also experienced some negative outcomes regarding their family. These participants were affected psychologically because they had to face short-term effects of cancer in the family including: changes in family members’ roles, less quality time with their parent with cancer, their parent being debilitated from their illness, having to take on more household responsibilities, and the financial strain on the family. Participants also identified impending long-term consequences of parental cancer, such as the potential of parental death. Similarly, in the study by Puterman and Cadell (2008), examining the experiences of young adult women, ages 20 to 32 years, who were presently experiencing parental cancer, participants reported that the timing of their parent’s cancer shocked them as they felt they were too young to lose a parent. They also feared and were saddened by the fact that their parent may not be present at important occasions in their lives. Some participants felt a desire to accelerate major life decisions such as marriage or having children so that the parent with cancer could be around for those experiences but no participants actually made those decisions.

The major themes that were identified in this study by Puterman and Cadell (2008) were “time”, “spirituality”, “hope”, “the meaning of cancer”, “relationships”, “coping”, and “family”. The study focused primarily on the theme of “time”, which included the following subthemes: “unexpected timing”, “uncertainty and waiting”, “being present”, “concerns for the future”, “acceleration of time”, “illness progression”, and “holidays”. Participants described the diagnosis stage as “chaotic” and the treatment stage as “being in limbo” because participants felt that they were always waiting for something to happen. Participants described the progression of
their parents’ illness and the medical appointments as a method of structuring time passing. Participants also discussed the idea of “firsts and lasts” for their parent such as the first time their parent needed help walking or their parent’s last birthday. Participants also stated that holidays like birthdays seem more significant and can also become more difficult as their parents’ illness progresses. These young adult women’s experiences of parental cancer revolved around uncertainty about the future, fears of personal susceptibility to cancer, and losing the parent with cancer.

Leedham and Meyerowitz (1999) found that the women who had lost a parent to cancer during their youth, did recollect having difficulties with schooling. Schmidt and Welsh (2010) examined social, academic and personal adjustment issues and benefits. Some students said that they became more motivated to do well in their schooling but that they also had more difficulties concentrating on their schoolwork. Students also found it challenging to find time to spend with their ill family member at home and to devote time to their assignments.

Despite the negative outcomes of parental cancer, some studies found that participants often experienced positive outcomes as well (Leedham & Meyerowitz, 1999; Levesque & Maybery, 2012; Schmidt & Welsh, 2010). Leedham and Meyerowitz (1999) found that their participants, the female adult offspring who experienced parental cancer in their youth, became closer to their sick parent, other family members, and friends and they gained more appreciation of others. Similarly, Levesque and Maybery (2012) examined the experiences of the adult offspring of people with cancer and found that two of the major themes, relating to positive outcomes, were participants changing the relationship with their sick parent and discovering the importance of family. Participants mentioned solving former conflicts so that their relationship and connection with their parent could be enhanced (Levesque & Maybery, 2012). Participants
discovered the importance of family and they experienced improved relationships with other family members (Levesque & Maybery, 2012). When Schmidt and Welsh (2010) examined how facing a family member’s illness affects students’ adjustment to university life, one of the areas they focused on was personal adjustment issues and benefits. Some students reported becoming closer to their friends and having more appreciation for the support in their lives as positive effects of their family members’ illness (Schmidt & Welsh, 2010).

Leedham and Meyerowitz (1999) found that women who had lost a parent to cancer identified with becoming a stronger person because of the experience. Participants experienced changes in their outlook of life and gained more inner strength (Leedham & Meyerowitz, 1999). In the study by Schmidt and Welsh (2010), more students reported experiencing negative effects on their personal and emotional adjustment than those who identified positive effects. Students who identified negative effects mentioned feeling burdened by their family members’ illness, while those who experienced positive effects mentioned growing from the experience (Schmidt & Welsh, 2010). Levesque and Maybery (2012) found that adult offspring of people with cancer altered their life priorities, and experienced personal development and growth as well. Participants described the positive changes that they experienced in their outlook on life with comments such as “I don’t take life so seriously” and “Live for the day”. Participants also described viewing experiences in their life as “learning curves” (Levesque & Maybery, 2012).

Some of the studies showed that people who had experienced parental cancer became more conscious of their own cancer risk (Leedham & Meyerowitz, 1999; Levesque & Maybery, 2012; Patterson & Rangganadhan, 2010). Patterson and Rangganadhan (2010) found that their participants, who were young adults and adolescents, needed more information about cancer, and how to reduce their own chances of developing cancer. Leedham and Meyerowitz (1999) found
that the women they interviewed had increased awareness of their own personal cancer risk, an increased understanding of cancer, and also problems with their physical health during their parent’s illness. Participants also discussed having altered views of health and death (Leedham & Meyerowitz, 1999). Likewise, Levesque and Maybery (2012) found that their adult participants discussed becoming more aware of their own risk of developing cancer and which preventable measures they could take to reduce their risk. These behaviours that participants identified were sun protection, the need for regular medical appointments and their personal medicine usage, and the importance of diet. Participants also became more aware of what death means to themselves and others and they experienced increased levels of compassion. Some participants also discussed being aware of how lifestyle choices may have influenced their parent’s cancer diagnosis.

2.6.1 Relevance of Examining Young Adults’ Experience of Parental Cancer

The experience of parental cancer at any point and especially during young adulthood is unexpected, but in young adulthood, it is also incongruent with social expectations of when someone has to face the life-threatening illness of a parent and the possible death of that parent (Puterman & Cadell, 2008). Parental cancer can be a traumatic event for the offspring, regardless of the type of cancer that the parent is facing (Mosher & Danoff-Burg, 2005). Young adults who are students and are dealing with a parent’s illness are also expected to confront issues in adjustment to university or college because of the separation from their families and their increased independence (Schmidt & Welsh, 2010). A student’s well-being can be affected by his or her attachment to his or her parent, his or her coping mechanisms, and social support. If a student doesn’t have adequate support or methods of coping prior to a family member becoming ill, then the student’s well-being may suffer, especially if the illness becomes severe.
(Schmidt & Welsh, 2010). The majority of young adults haven’t gone through the experience of parental cancer and therefore a young adult who has experienced this may not have the required amount of social support (Puterman & Cadell, 2008). These young adults are also learning to develop their own identity while trying to balance time with their family and friends and time spent on academic pursuits (Schmidt & Welsh, 2010).

There has been research examining the negative outcomes of parental cancer but there has been less research examining the positive results of having the experience of parental cancer (Levesque & Maybery, 2012). The experience of parental cancer can potentially lead to the offspring changing the relationship with their sick parent, understanding the importance of family, altering their life priorities, and participating in personal development (Levesque & Maybery, 2012). Personal development may include having an increased awareness of personal risk of cancer and preventative measures that can be taken to reduce that risk (Levesque & Maybery, 2012). Young adults who have had the experience of parental cancer may begin to be fearful for their own risk of cancer so they can possibly find comfort in determining their actual cancer risk and learning about early detection and screening by speaking with their doctor (Puterman & Cadell, 2008).

Research has also focused on the experiences of children and adolescents who have had a parent with cancer even though the majority of cancer patients’ children are actually adults (Levesque & Maybery, 2012). There is a need to understand the experiences of young adults so that their needs may be met more effectively by health, education and social service organizations (Levesque & Maybery, 2012). Even though the adult offspring may live away from their parent, this doesn’t mean that he or she isn’t affected by the experience or deeply involved with it (Levesque & Maybery, 2012). There is a need for research examining adult
offsprings’ experiences of cancer and cancer relapse in their parents and the role that the adult offspring plays in caregiving and treatment decisions during end-of life care (Mosher & Danoff-Burg, 2005). Research has also focused predominantly on the daughters of women with breast cancer so there is more exploration needed to understand the great diversity of experiences of parental cancer (Mosher & Danoff-Burg, 2005).

Researching the experiences of parental cancer in young adults (ages 18 to 29 years), both male and female, will address the need for understanding the experiences of this age group while also including a more diverse level of experiences, which has been absent in the literature (Levesque & Mayberry, 2012; Mosher & Danoff-Burg, 2005). Researching the experiences of young adults who have the experience of parental cancer and are also attending a post-secondary institution will allow for an increased understanding of how the cancer experience influences a young adult’s adjustment to college or university life, which needs to be explored further in the literature (Mosher & Danoff-Burg, 2005). Furthermore, an increased focus on the positive outcomes of the experience, especially relating to the offspring’s personal health, will increase the understanding of the positive outcomes of parental cancer in the young adult, student population, which is absent in the literature (Levesque & Maybery, 2012).
3.0 Research Objectives

The research objectives of this study are to examine:

(a) young adult, university students’ perceptions and beliefs about cancer, its causes, and prevention strategies.

(b) these students’ perceived outcomes of their lived experience with parental cancer.

(c) these students’ coping strategies and support systems used during their experience of parental cancer.

(d) the influence of these students’ experiences with parental cancer on their life as a university student.

(e) these students’ personal health beliefs and behaviours since experiencing parental cancer.
4.0 Methods

4.1 Research Design and Paradigm

This study was cross-sectional and used semi-structured interviews, which were then analyzed using thematic analysis. This study uses qualitative methodology stemming from a social constructionist paradigm (Gergen, 2001). A qualitative study focuses more on gaining a deeper understanding of a complex issue in human life than on its results’ generalizability. It goes beyond the superficial aspects of a phenomenon and instead aims to find discernable meanings (Crouch & McKenzie, 2006). The social constructionism paradigm emphasizes that knowledge is achieved through relationships and communities and that the world cannot be viewed objectively (Gergen, 2001). Our understanding of our world and our own realities are constructed through our languages, relationships, and cultures (Gergen, 2001).

The guiding qualitative methodology that was used is phenomenology. Phenomenology aims to understand and explain the lived experiences of individuals who have experienced a particular phenomenon while focusing on how participants see their world and their experience (Finlay, 2011). It allows participants to have their own voice heard and it also allows both themselves and the researcher to have a more in-depth understanding of the phenomenon (Finlay, 2011).

Our ontological assumptions are from a relativist stance and our epistemological assumptions are from an interpretivist stance (Snape & Spencer, 2003). Ontology describes the beliefs of what there is to know about our world (Snape & Spencer, 2003). Relativism dictates that to understand our own realities, we use meanings that are constructed socially and that there are many different kinds of social constructions created by people rather than one shared reality (Snape & Spencer, 2003). Epistemology is concerned with methods of learning and understanding our social world and interpretivism dictates that the researcher and the social
world are interconnected. Interpretivism dictates that the results of research will always be influenced by the researcher’s own values and knowledge and therefore they can not be completely objective. The researcher has the obligation of being open about his or her own beliefs and assumptions (Snape & Spencer, 2003).

4.2 Measures

4.2.1 Guiding Theoretical Constructs

Multiple theoretical constructs from the Health Belief Model, the Theory of Planned Behaviour, and the Stress and Coping Theory were used to guide the development of semi-structured interview questions. The primary guiding theory is the Health Belief Model (Rosenstock, 1974). The Health Belief Model includes perceived susceptibility to disease, perceived severity of disease, perceived benefits of taking preventive action, perceived barriers to taking preventive action, cues to action, and self-efficacy. These factors can help predict why someone would try to screen for, prevent, or manage an illness (Glanz, Rimer, & Viswanath, 2008). These factors are defined below:

(a) Perceived Susceptibility: Perceived susceptibility is the extent to which individuals believe they are susceptible to a certain illness or disease (Glanz et al., 2008).

(b) Perceived Severity: Perceived severity is a person’s perception of how severe an illness is and how serious it would be if untreated. A person takes into consideration the clinical consequences such as disability or death and the social consequences such as the effects on family or work (Glanz et al., 2008).

(c) Perceived Benefits: Perceived benefits are the positive outcomes that would be achieved if someone were to make a health behaviour change. If individuals perceive themselves at risk of developing an illness, the next element that will determine behaviour change is
the perceived benefits of implementing a specific health behaviour change (Glanz et al., 2008).

(d) *Perceived Barriers:* Perceived barriers are the cost of implementing a health behaviour or factors that inhibit behaviour change. The costs of implementing a behaviour are then compared with the perceived benefits (Glanz et al., 2008).

(e) *Cues to action:* Cues to action are triggers for implementing a new health behaviour. These triggers are dependent on current health beliefs (Baban & Craciun, 2007; Glanz et al., 2008). Cues to action can either be internal or external (Baban & Craciun, 2007; Glanz et al., 2008). Internal cues could be hurting yourself or suffering illness symptoms (Baban & Craciun, 2007). External cues could be someone close to you getting diagnosed with a disease like heart disease or learning about the negative effects of low physical activity in the media (Baban & Craciun, 2007).

(f) *Self-efficacy:* Self-efficacy is how confident people are that they can implement a behaviour change (Glanz et al., 2008). Self-efficacy was added to the Health Belief Model later because it addresses overcoming perceived barriers through feeling competent.

A second guiding theory is the Theory of Planned Behaviour (Ajzen, 2006). This theory evolved from the Theory of Reasoned Action (Glanz et al., 2008). The theory of planned behaviour claims that behavioural intention is the strongest predictor of behaviour change outcomes. The determinants of intention in this theory are:

(a) *Attitudes:* Attitudes are a person’s beliefs about the outcome of implementing a new behaviour (Glanz et al., 2008).
(b) **Subjective norms**: Subjective norms are a reflection of a person’s beliefs that significant people in their life want them to adopt a certain behaviour (Baban & Craciun, 2007). Subjective norms are determined by normative beliefs, which are the perceived expectations for behaviour from important and influential people in a person’s life. Normative beliefs include injunctive social norms and descriptive norms. Injunctive social norms represent the social approval of a behaviour change by significant others and descriptive norms represent what those significant others’ behaviours actually are.

(c) **Perceived behavioural control**: Perceived behavioural control is determined by control beliefs which focus on whether there are facilitators or inhibitors to behaviour change and if so, to what extent they inhibit or facilitate the person’s ability to instil behaviour change.

The third theory guiding this study is the Stress and Coping Theory (Lazarus & Folkman, 1984). This theory indicates that stress comes from relationship between a person and his or her environment and how taxing that person perceives the relationship on his or her own resources or capabilities. The two mediators of this relationship are:

(a) **Cognitive appraisal**: Cognitive appraisal consists of an individual assessing the impact an environment may have on him or her and then assessing how the environment may affect him or her. Primary cognitive appraisal deals with how an environment would affect the individual or those who are important to him or her, and secondary cognitive appraisal deals with what an individual can do to reduce the risk of a situation and change the prospects of it to be of benefit instead.

(b) **Coping**: Coping consists of managing the relationship between a person and the environment, where that relationship is perceived as being taxing. Coping is based on
internal and external demands of the relationship between a person and the environment and the cognitive and behavioural efforts that the person makes to manage these internal and external stressors.

This study used a combination of constructs from the Health Belief Model, the Theory of Planned Behaviour, and the Stress and Coping Theory. The constructs that were included were perceived susceptibility, perceived severity, perceived benefits, perceived barriers, cues to action, self-efficacy, attitudes, subjective norms, perceived behavioural control, cognitive appraisal, and coping.

4.2.2 Interview Guide

This study used semi-structured interviews using the interview guide (See Appendix C) to obtain data. The interview was semi-structured to allow for further questions if the participants were discussing a topic that could be relevant but wasn’t included with one of the questions in the interview guide. Interviews were private and lasted approximately 1-1.5 hours depending on the participant.

4.2.3 Participants

There were 17 participants in the study. A small sample of 20 or less participants has its advantages because it allows the researcher to be closely connected with the participants and focus on the research objectives and/or questions in depth (Crouch & McKenzie, 2006). Participants were between the ages of 18 to 27 years of age and were attending university. Fourteen women and three men were interviewed. Fourteen participants were taking undergraduate studies and three participants were enrolled in graduate studies. The majority of participants identified as White but one participant identified as Jewish and another participant identified as Chinese. Ten participants’ parents currently have cancer and 7 participants’ parents
had cancer in the past while the participants’ were between the ages of 18 and 29. Similar to the eligibility criterion used by Levesque and Maybery (2012) to account for grief and the sensitivity of the subject of cancer, if participants had experienced bereavement of their parent with cancer, then the bereavement would have occurred at least six months prior to participating in the study. Participants were recruited through poster advertisements, word of mouth, and social media.

4.2.4 Demographics

Demographic information was collected (see Appendix B) at the beginning of the interview session. The demographic questionnaire is based on the 2011 National Household Survey Questions (Statistics Canada, 2012). This demographic information was used to describe the contexts of the participants in the analysis of data.

4.3 Data Analysis

Thematic analysis was used to analyze the content of the semi-structured interviews. Thematic analysis is used to identify and analyze patterns or themes in collected data (Braun & Clarke, 2006). Themes capture the important components of the data set that answer research questions or help reach research objectives (Braun & Clarke, 2006).

The methods in the textbook Applied Thematic Analysis (Guest, MacQueen, & Namey, 2012) regarding identifying themes and coding were one of the resources used to guide the organization and analysis of the interviews. The elements of thematic analysis are defined below:

(a) *Theme*: A theme is a unit of meaning observed in the transcriptions.

(b) *Code*: A code provides a description of the boundaries of meaning for a theme.

(c) *Coding*: Coding is the process of linking designated codes with segments of text.
The first author and the third author began the analysis of a transcribed interview by identifying text that had meaning and creating a codebook. The codebook organizes the meanings/themes that are observed in the transcription. These meanings/themes were then organized according to each interview question. The codebook was constantly developed because as more interviews were transcribed, more categories and codes emerged. The codebook used a definition method for each code that includes:

(a) *Code label:* A code label is the short title (one or two words) given to a code that signifies its overall meaning easily.

(b) *Short definition:* A short definition is one or two sentences long and it describes the theme that the code encompasses.

(c) *Example:* An example is a quote that could be seen in the text that fits under this particular code.

Themes were identified and codes were applied based on the principles of open, axial, and selective coding (Neuman and Robson, 2015). The first and third authors began the analysis of the transcribed interviews with open coding (Neuman and Robson, 2015). Open coding included identifying text that had meaning, assigning initial code labels, and giving a brief description of the concepts. The first author used memo writing to keep notes of her thoughts and opinions on each interview and these notes facilitated the exploration and conceptualization of the data (Birks Chapman, & Francis, 2008). The next step was to begin axial coding (Neuman and Robson, 2015). The first and third author did a second pass of the interviews and the preliminary codes and from there combined codes, renamed codes, or eliminated codes because of their lack of richness. To complete the analysis, the first and third author completed selective coding (Neuman and Robson, 2015). This included grouping important themes together and
making connections between various themes to facilitate the overall analysis. The analysis was conducted using NVivo software.

4.4 Procedure

A pilot study was conducted before actual interviews began. The pilot study consisted of an interview with someone who had post-secondary education and had experienced parental cancer. The pilot study’s purpose was to test the questions included in the interview guide to determine if they were understood correctly and whether the questions generated sufficient discussion. The pilot interview was also an opportunity to practice interviewing skills and using audio-recorders.

Participants were recruited through poster advertisements (See Thesis Appendix: Appendix A) word of mouth, and in-class announcements at the University of Guelph, City of Guelph campus. The University of Guelph offers a wide selection of programs and there are approximately 17,436 undergraduates and 2,131 graduate students (Office of Registrational Services, n.d.). International students at the University of Guelph also represent over 100 different countries (Office of Registrational Services, n.d.).

Participants were chosen using purposive sampling and snowball sampling. Purposive sampling selects participants who will be most appropriate for answering the research questions or achieving the research objectives (Marshall, 1996). Snowball sampling occurs when current participants refer people they know of to the study (Lewis-Beck, Bryman, & Liao, 2004). The number of participants needed to answer the research questions becomes clear as data saturation occurs (Marshall, 1996). Data saturation occurs when new themes stop emerging (Marshall, 1996). A small sample of 20 or less participants has its advantages because it allows the researcher to be closely connected with the participants and focus on the research objectives.
and/or questions in depth (Crouch & McKenzie, 2006). This study aimed to recruit approximately 20 participants following the guidelines of Crouch and McKenzie (2006).

Participants were invited to participate in a study about the experience of parental cancer. Participants were informed of the general purpose of the study. To reduce levels of social desirability, the specific research objectives were not discussed until after the interview was completed. Meetings with potential participants were arranged by email and/or phone, depending on the participant’s preference (See Appendix E). The meetings occurred on campus in a private and convenient location (i.e., private office or classroom). Upon arriving at the designated meeting place, the first author welcomed the participant and introductions were made. The first author explained to the participant what to expect in the 1-1.5 hour interview. The first author also reminded the participant that if he/she felt uncomfortable or wished to end the interview, he/she could do so at any time. The participants were informed that only the researcher and the researcher’s advisor will have access to the names of the participants. Pseudo-names as well as a numbering system were used for confidentiality and publication purposes, so that identities are never disclosed in the written thesis or in any publications. The participants had the opportunity to ask any questions they may have and then they were invited to give informed consent to participate in the study.

The interviews were audio-recorded to aid in their transcription. Two audio recording devices were used to prevent the loss of an interview if one of the devices malfunctioned. The participants were informed, prior to giving informed consent, through email, that the interviews were going to be audio-recorded. The audio-recorders were turned on first and then the researcher began a semi-structured interview. The interview followed the interview guide questions in numerical order but detracted from it at times with spontaneous questions,
depending on the participant. Once the last question was answered, the audio-recorders were turned off. The participants were each thanked for their participation and they were provided with a $20 token of appreciation. The topic of cancer is sensitive and because of this, appropriate resources from the University of Guelph Health services and other sources were provided to every participant (see Appendix D). These resources address bereavement, cancer and the family, and family counselling and support services offered on campus and in the community. Interviews occurred while recruitment of other participants occurred, so participants were asked not to discuss their participation in the study with other students or participants.

After the interviews were conducted, the audio-tapes were downloaded on the first author’s laptop and shared with the third author. The first author and the third shared the responsibility of transcribing the interviews in Microsoft Word using pseudo-names and numbers to label each interview. Any printed transcriptions were stored in a locked filing cabinet throughout the research process. The computer that was used during transcription and any files relating specifically to the study were encrypted. Once transcription was complete, the first author and the third worked together on the thematic analysis of the transcripts. The first author imported the transcriptions into NVivo 10 for Mac. The third author also participated in the analysis of the same transcripts except she did her analysis in Microsoft Word. The codebook was created and adapted throughout the analysis of the transcripts. The first author and the third met regularly in person to develop consensus on the codebook and to perform the various stages of coding.
The Experience of Parental Cancer Among Young Adult University Students and its Influence on Health Beliefs and Behaviours

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Abstract

Cancer is a disease that can have negative as well as some positive outcomes for the survivor, caregiver, and offspring. To date, there has been little research on the experiences of young adult offspring. When these offspring are also university students, they can experience unique challenges. This study aimed to explore the experience of parental cancer among young adult university students by interviewing 17 university students and using thematic analysis. Participants faced challenges with their friendships but found that the experience brought their family closer. Most participants gained an altered and more positive life outlook. Parental cancer caused distress and led to a decreased ability to focus at school but some participants found their experience to be a source of motivation. Participants became more health conscious, made lifestyle changes and felt they were more susceptible to cancer. The university atmosphere, time, and money were identified as barriers to making lifestyle changes.

Keywords

behavior change, cancer, health and wellbeing, interviews, semistructured, lived experience, self-efficacy, research, qualitative, social constructionism, young adults
Canadians have a 2 in 5 chance of developing cancer at some point in their lifetime (Canadian Cancer Society’s Advisory Committee on Cancer Statistics, 2014). It is estimated that in 2014 there will be 191,300 new cases of cancer and 76,600 people will die from cancer (Canadian Cancer Society’s Advisory Committee on Cancer Statistics (2014). Although 5-10% of cancer types occur in relation to genetic disposition, 90-95% of cancers occur due to lifestyle and environmental factors (Anand et al., 2008). The five leading behavioural and dietary risks for developing cancer are: tobacco use, alcohol use, overweight and obesity, physical inactivity, and low fruit and vegetable intake (World Health Organization, 2013). For those with cancer, behavioural risk factors can influence complications from treatment, likelihood of cancer recurrence post-treatment, quality of life, subsequent primary cancer incidence, and the incidence of other chronic diseases such as cardiovascular disease and diabetes (Coups & Ostroff, 2005). Cancer survivors are not currently meeting guidelines for physical activity, nutrition, or weight status (Coups & Ostroff, 2005; Courneya, Katzmarzyk, & Bacon, 2008). Unfortunately, cancer survivors face a number of unique physical and psychosocial challenges post-treatment that can influence their physical activity levels, eating habits, stress management, and overall well-being (Howell et al., 2012).

Research about the cancer experience has mostly focused on the dysfunction and challenges that occur but there is also considerable research suggesting that a large percentage of cancer survivors can adjust well and experience psychological growth after receiving a cancer diagnosis (Bellizzi, 2004; Thornton, 2002). Cancer is a disease that not only affects the person with cancer but also family members, friends, and co-workers of that individual (Kim & Given, 2008). Caregivers can also experience post-traumatic growth from their caregiving experience because they are heavily involved in the cancer experience itself (Thornton & Perez, 2006).
Caregivers can experience positive outcomes from their caregiving experience such as: control over their own life, appreciating others, finding meaning in their life, and changing attitudes and values in their life (Kang et al., 2013).

The offspring of a person with cancer have to view the physical and emotional suffering of their parent and prepare for the possible loss of that parent, and this can be a traumatic experience regardless of the type of cancer (Mosher & Danoff-Burg, 2005). The experience of parental cancer during young adulthood is unexpected and incongruent with social expectations of when someone has to face the life-threatening illness of a parent and the possible death of that parent (Puterman & Cadell, 2008). Although traumatic, the experience of parental cancer may influence the adult offspring in becoming more aware of their personal cancer risk and also their own inevitable mortality (Mosher & Danoff-Burg, 2005). Young adults, who are students and are dealing with a parent’s illness, are also expected to confront issues in adjustment to university or college because of the separation from their families and their increased independence (Schmidt & Welsh, 2010).

The experience of parental cancer can potentially lead to the offspring changing the relationship with their sick parent, understanding the importance of family, altering their life priorities, and participating in personal development (Levesque & Maybery, 2012). Personal development may include having an increased awareness of personal risk of cancer and preventive measures that can be taken to reduce that risk (Levesque & Maybery, 2012). Research has also focussed on the experiences of children and adolescents who have had a parent with cancer even though the majority of cancer patients’ children are actually adults (Levesque & Maybery, 2012). More research examining the positive outcomes of having a parent with cancer, especially the experiences of young adults, is needed (Levesque & Maybery, 2012). There has
also been little research examining young adults who are attending a post-secondary institution and have experienced their parent having cancer (Schmidt & Welsh, 2010).

Methods

The research objectives of this study are to examine:

(f) young adult, university students’ perceptions and beliefs about cancer, its causes, and prevention strategies.

(g) these students’ perceived outcomes of their lived experience with parental cancer.

(h) these students’ coping strategies and support systems used during their experience of parental cancer.

(i) the influence of these students’ experiences with parental cancer on their life as a university student.

(j) these students’ personal health beliefs and behaviours since experiencing parental cancer.

Participants

There were 17 participants in the study. The number of participants needed to answer the research questions becomes clear as data saturation occurs (Marshall, 1996). Data saturation occurs when new themes stop emerging (Marshall, 1996). A small sample of 20 or less participants has its advantages because it allows the researcher to be closely connected with the participants and focus on the research objectives and/or questions in depth (Crouch & McKenzie, 2006). Participants were between the ages of 18 to 27 years of age and were attending university. Fourteen women and three men were interviewed. Fourteen participants were taking undergraduate studies and three participants were enrolled in graduate studies. The majority of
participants identified as White but one participant identified as Jewish and another participant identified as Chinese. Ten participants’ parents currently have cancer and seven participants’ parents had cancer in the past, while the participants were between the ages of 18 and 29. Similar to the eligibility criterion used by Levesque and Maybery (2012) to account for grief and the sensitivity of the subject of cancer, if participants had experienced bereavement of their parent with cancer, then the bereavement would have occurred at least six months prior to participating in the study.

Participants were recruited through poster advertisements, word of mouth, and social media. Participants were chosen using purposive sampling and snowball sampling. Purposive sampling selects participants who will be most appropriate for answering the research questions or achieving the research objectives (Marshall, 1996). Snowball sampling is where current participants refer people they know of to the study (Lewis-Beck, Bryman, & Liao, 2004).

Research Design and Paradigm

The study was cross-sectional and we used semi-structured interviews to yield transcripts of data, that were analyzed using thematic analysis. We used qualitative methodology stemming from a social constructionist paradigm (Gergen, 2001). When using qualitative methodology, we focus more on gaining a deeper understanding of a complex issue in human life than on the generalizability of results. It goes beyond the superficial aspects of a phenomenon and instead aims to find discernable meanings (Crouch & McKenzie, 2006). The social constructionism paradigm emphasizes that knowledge is achieved through relationships and communities and that the world cannot be viewed objectively (Gergen, 2001). Our understanding of our world and our own realities are constructed through our languages, relationships, and cultures (Gergen, 2001).
The guiding qualitative methodology that was used is phenomenology. Phenomenology aims to understand and explain the lived experiences of individuals, who have experienced a particular phenomenon. It also focuses on how participants see and understand their world and their experience (Finlay, 2011). It allows participants to have their own voice heard and it also allows both themselves and the researcher to have a more in-depth understanding of the phenomenon (Finlay, 2011). In our study, the lived experience is having a parent with cancer.

Our ontological assumptions are from a relativist stance and our epistemological assumptions are from an interpretivist stance (Snape & Spencer, 2003). Ontology describes the beliefs about what there is to know about our world (Snape & Spencer, 2003). Relativism dictates that to understand our own realities, we use meanings that are constructed socially and that there are many different kinds of social constructions created by people rather than one shared reality (Snape & Spencer, 2003). Epistemology is concerned with methods of learning and understanding our social world and interpretivism dictates that the researcher and the social world are interconnected. Interpretivism dictates that the results of research will always be influenced by the researcher’s own values and knowledge and therefore they cannot be completely objective. The researcher has the obligation of being open about his/her own beliefs and assumptions (Snape & Spencer, 2003).

**Guiding Theoretical Constructs**

Multiple theoretical constructs from the Health Belief Model, Theory of Planned Behaviour, and Stress and Coping Theory were used to guide the development of the semi-structured interview questions (see Appendix A). The primary guiding theory was the Health Belief Model (Rosenstock, 1974). The Health Belief Model examines perceived susceptibility to disease, perceived severity of disease, perceived benefits of and perceived barriers to taking preventive
action, cues to action (i.e., triggers for implementing behaviours), and self-efficacy (i.e., confidence to engage in a behaviour). These factors can help predict why someone would try to screen for, prevent, or manage an illness (Glanz, Rimer, & Viswanath, 2008). The Theory of Planned Behaviour (Ajzen, 2006), which evolved from the Theory of Reasoned Action, claims that behavioural intention is the strongest predictor of behaviour change outcomes. The determinants of intention in the Theory of Planned Behaviour are attitudes (i.e., extent to which a behaviour is valued), subjective norms (i.e., perception that significant others expect you to do or not do a behaviour), and perceived behavioural control (i.e., perceived ability to do a behaviour) (Ajzen, 2006; Glanz et al., 2008). The Stress and Coping Theory postulates that stress comes from the relationship between a person and his or her environment and how taxing that person perceives the relationship on his/her own resources or capabilities (Lazarus & Folkman, 1984). The two mediators of this relationship are cognitive appraisal and coping. Primary cognitive appraisal deals with how an environment would affect the individual or those that are import to him/her and secondary cognitive appraisal deals with what an individual can do to reduce the risk of a situation and change the prospects of it to be of benefit instead. Coping consists of managing the relationship between a person and the environment, where that relationship is perceived as being taxing. Coping is based on internal and external demands of the relationship between a person and the environment and the cognitive and behavioural efforts that the person makes to manage these internal and external stressors.

Data Collection

This study received ethics approval from the university’s research ethics board. The interviews occurred on campus in a private and convenient location (i.e., private office or classroom). A pilot study was conducted before the main interviews. The pilot study consisted of an interview
with someone who had post-secondary education and had experienced parental cancer. The pilot study’s purpose was to test the questions included in the interview guide to determine if they were understood correctly and whether the questions generated sufficient discussion. The pilot interview was also an opportunity to practice interviewing skills and using audio-recorders.

The main interviews were audio-recorded to aid in transcription. The participants were provided with a $20 token of appreciation at the end of the interview. The topic of cancer is sensitive and because of this, appropriate resources were also provided at this time. These resources addressed bereavement, cancer and the family, and family counselling and support services offered on campus and in the community.

**Data Analysis**

NVivo 10 for Mac was used to manage the data. Thematic analysis was utilized to analyze the transcripts. The first and third authors independently performed open coding, which entailed assigning preliminary themes and codes in the margins of transcripts, as they read the transcripts for the first time (Neuman & Robson, 2015). The first author used memo writing to keep notes of her thoughts and opinions on each interview/transcription, and these notes facilitated the exploration and conceptualization of the data (Birks, Chapman, & Francis, 2008). A constant comparison approach was used to develop these preliminary themes. Both authors independently generated a list of themes by continually referring to themes already generated (Flick, 1998; Morse & Richards, 2002). Next, both authors worked together to perform axial coding (Neuman and Robson, 2015). Both authors read the transcripts again and examined how the preliminary themes are connected and then organized them into larger clusters. Both authors agreed upon a master list of themes, definitions of themes, and codes for themes. Both then independently performed selective coding as they read each transcript again to apply the master list of codes to
segments of text and to highlight good illustrations of themes (Neuman & Robson, 2015).

Results

Perceptions and Beliefs About Cancer

We began the discussion about participants’ perceptions and beliefs about cancer by asking what participants thought were causes of cancer. We then discussed what they believed had caused their parents’ cancer. In this section, we will discuss participants’ thoughts on the causes of cancer in general and in their parent’s specific case, the prevention of cancer, and whether cancer is concerning and why.

Causes. Participants believed that cancer does not stem from one thing but that it has a variety of causes. A participant (P7) described this idea by stating “I think there’s really not one set thing. There seems to be a lot of possible things that can affect the cells and then change everything around and cause cancer.” The various causes identified were a combination of environmental, genetic, and lifestyle factors. For example, a participant (P8) described how genetics and the environment could combine and cause cancer.

I think that there are a lot of things. It's genetic. It's also environmental. . . . I'm sure that it could be that you could have a genetic predisposition for it but because of the way that you are raised or the environment, which you live in, it could be altered.

Most participants had an understanding that the development of cancer could be related to a person’s genetics. Some participants discussed how certain individuals, regardless of environment or lifestyle, have a genetic predisposition for developing cancer. A participant (P7) described this connection as “I feel that having family members who have gotten cancer, you’re
more likely to get it because I feel that there may be cells, where it’s in the DNA and it’s more susceptible to getting cancer.”

In general, not eating healthy or being physically inactive were identified as possible risk factors for cancer, and all participants were aware of the connection between smoking and cancer and sun exposure and skin cancer. A participant (P5) described a thought about smoking and tanning, “People hate smoking so much because of lung cancer but I think tanning beds and people laying and baking in the sun is just as stupid.” Participants did not recognize lifestyle as being the main contributing cause in the incidence of their parent’s cancer but they did recognize certain aspects of lifestyle that could have played a role. These factors included eating an unhealthy diet, not exercising, and having high stress levels. A participant (P8) described her mother’s lifestyle as “she was never good with eating proper things and working out . . . so I think that also took a toll on it.”. A participant (P16) described how his father not taking care of himself in general increased his risk of developing cancer.

I think he just wasn't taking care of himself enough. . . . People that take care of themselves all the time can still get cancer . . . but I think it increases your chances when you neglect your body.

Although participants mentioned poor diet and physical inactivity as risk factors for their parent, they elaborated on the role that stress played in their parent’s cancer. Participants often described their parent’s health as being good except for their stress levels. A participant (P17) described how she thinks stress played a vital role in her mom’s cancer.

This isn't genetic. There's nothing in our background and I honestly think it was stress with her. I think it just wore her down and it let that [cancer] happen. . . . she would be
working twelve hour days then come home and run the family, take care of the farm, and go back to work for another twelve hours. After a few years of doing that, all of a sudden she had cancer.

Another participant (P2) explained how stress not only played a direct role in the development of her mother’s cancer but also how it influenced her mother’s lifestyle.

I know my mom had led a very high stress life. She had three kids, worked full-time and managed a household. Then she also just had the lifestyle, where you stop taking care of yourself when you have kids. Not stop taking care of yourself, but you're not the first person on your list, when you have kids. So she wasn't taking as good care of herself as she should have. There were earlier signs that she should've gotten checked out which may have stopped it from going so bad, but I believe stress is the number one key.

Though participants offered their ideas of what caused their parents’ cancer, a large portion of participants were still uncertain as to what causes cancer in general and in their parent’s specific case. A participant (P10) stated, “Honestly I don't even know. Bad luck I guess.”

Prevention. To prevent cancer, most participants identified lifestyle factors alone. Participants believed that living a generally healthy lifestyle could reduce a person’s risk of developing cancer or at least help people battle cancer if they did develop it. For example, a participant (P17) commented that “just generally living a more healthy life can help take care of your stress and obviously not smoking, not harming your body all the time.” Another participant
(P12) explained how being health conscious could help someone reduce his or her risk of developing cancer.

> I think it would just be more of a holistic attitude towards your health, from eating the right foods to exercising and watching your weight . . . just having a holistic healthy lifestyle, exercising, eating right, and trying to be aware of what's going in your body.

Another participant (P11) described how a combination of lifestyle factors could be addressed to reduce someone’s cancer risk.

> For things like skin cancer . . . wearing sunscreen and staying out of the sun. Eating less charred food from the barbeque, nitrates and stuff like that from cured meats. Washing your fruit, and staying away from things like pesticides, and microwaves. Some people are afraid of standing in front of microwaves. I don't know how true that is but sometimes I find myself standing in front and then I'll move just in case.

*Cancer is concerning.* Participants unanimously agreed that cancer is something to be concerned about. The largest concern that they had was the ever-increasing prevalence of cancer. A participant (P8) thought, “anybody's susceptible to it and it's just a really scary scary thing.” Another participant (P16) described his concern for the increase in cancer cases in society.

> I would say that because more and more Canadians and people internationally are being affected by it and it's almost hard to explain. It's like a pandemic right now. . . . Everyone you know has been affected in some way by cancer. I don't know one individual who I can ask “Do you know anyone who has been affected?”, who would say no. They'll be like oh, my cousin, my father.
Many participants thought that cancer was concerning because of the number of deaths it causes. Some participants discussed how having a parent could affect a person greatly, especially when there is a loss of that parent. A participant (P12) described how cancer could potentially affect a person.

Parental cancer in general can be huge especially . . . children need their parents. . . . So the outcomes are varied and they can be anything from a positive experience to full out losing one of your parents and it being sort of a devastating thing.

Many participants mentioned how difficult cancer was on the family. For example, a participant (P2) explained the emotional upset that cancer can cause a family to experience.

It really hurts families emotionally. You don't know what’s going to happen. Yes, a lot of people get cured and thank God for that, but there's also those times when you get the news and it can just completely destroy a family.

The Outcomes of Having a Parent with Cancer

Participants were asked what they believed were the outcomes of having a parent with cancer, based on their personal experience. They were then asked to elaborate on both negative and positive outcomes, if any. Participants discussed the emotional turmoil that they felt, how cancer affected their friendships for good and for worse, and how cancer affected their family dynamics and relationships. Participants also discussed positive personal outcomes from their experience including greater maturity, having an improved ability to relate to other people, and having a more positive outlook on life.
Emotional turmoil. Participants discussed feelings of sadness and anxiety that they had because of their parents’ cancer. A participant (P9) described how her emotions affected her energy levels by saying “It makes me a lot more tired from crying. I feel tired a lot more than I would ever feel before.” Another participant (P13) became less tolerant when she found out her dad had cancer and she described this as “Last winter was a lot harder [snowboard instructing]. . . . I found last winter my tolerance was off. The tiniest thing could set me off.” Another participant (P1) commented on how some days she is more emotional than others.

There are still sad days and that's usually my partner . . . talking to him and just being like “This sucks! Why does my dad have to have cancer? This isn't really fair.” . . . I think the hardest part is actually seeing my dad slow down and that's when I would go back and just feel . . . I can't believe that this guy, who five years ago was re-roofing our house, now needs a nap every afternoon.

Participants talked about re-occurring emotional outbursts, where they felt that they were not in control of their own emotions. A participant (P6) described her emotional outbursts and how they made her feel.

I don't think I can take it anymore. There are times when I just cry all of a sudden in my room and sometimes it happens when I'm waiting for the bus, which is super embarrassing. People just don't know what's going on. . . . It's just really hard because she was such a main . . . part of my life. I feel like I'm not really myself anymore.

The effects of parental cancer on friendships. Some participants claimed that there were few changes in their relationships but most participants identified small changes in their
relationships and in their outlook on these relationships. Participants spoke about their friends not being able to understand what they were going through. A participant (P2) explained how she lost friends during her experience by saying “I lost a lot of friends. Not lost a lot of friends but I didn't go out for social occasions. . . . I don't know what it was. I felt they didn't understand.”

Participants talked about how their experience with parental cancer made them realize whom their true friends really were. A participant (P10) discussed her experience with her roommates.

Last year, I lived with four other girls and only two of them knew so it was kind of hard. They would be like “why do you always stay home?” and I just don't want to tell them. It’s not really their business. It definitely made them distance themselves. . . . so they just didn't understand.

Participants often mentioned that they felt they had a different set of priorities in comparison to their peers. A participant (P1) talked about how, when she meets new people, they sometimes have a hard time understanding why she prioritizes her family so much.

I think it's pretty much like school, you just have a different set of priorities. Other people just want to go away or go out and party. . . . I'm having dinner with my parents on Saturday and that's okay . . . that's something. For especially casual acquaintances, that you're just getting to know, they want you to go out with them. It can be hard to explain why it's just so important that you actually go home and see your family instead of going out with them because they have the perception “Oh it's almost Christmas. You can go see your parents at Christmas” and it's like “Yes but it's nice to see them now too.”

Another participant (P6) made a comparison between her and her friends that made her feel that they did not understand her.
It’s just not the same for me . . . I have a sick mom and you have a healthy mom so it's really different. My mom was the main supporter in terms of emotional stuff and financially, so everything. My mom was just the centre of the family so I’m always worried if something happens to her, then I don’t really know what to do with my life. So I’m always thinking about that but my friends didn't really understand me.

Participants also discussed how they withdrew from their social life and certain friendships when their parent had cancer. A participant (P8) stated “I just kind of pushed everybody away and tried to deal with it on my own but I realized that's not really the most positive way.” Another participant (P10) talked about pushing particular friends, who did not understand, out of her life and focusing on the people who were there for her.

I obviously just backed away from everything and just stayed with my family and the ones who reached out to me . . . and then the other ones who just are like “Why don't you want to go out?” . . . Last year, I didn’t want to go out as much sometimes . . . so they just don't have any compassion I find.

Participants acknowledged that the sadness and the anxiety that they felt often made them withdraw from social outings. A participant (P4), who lost her mother, commented on how she withdrew from friendships without even realizing it at the time.

I don't think I coped that well. The next two years I was kind of a bit depressed . . . then I went on a semester abroad to Paris and I had an amazing time. I think that was kind of the same thing, where I just went away and kind of separated myself from it. Then when I came back from that . . . next year was a lot harder for me. I think I withdrew a lot from
a lot of my friends and stuff for about a year and I didn't even really realize I was doing it.

Participants discussed how it was sometimes hard to be social because they were dealing with thoughts of their parent’s cancer at home. A participant (P16) described how he could not put his friendships first, while he was dealing with his dad’s cancer.

It was a very stressful time . . . it was definitely hard and it affected my relationships. I didn't have time to put into them because I was so busy, and even my little bit of time that I had was going towards being back at home mentally and calling. . . . So obviously it puts a kind of strain on spending time with friends and people you care about.

Although participants faced challenges with maintaining their friendships, many participants also mentioned that their experience with parental cancer allowed them to foster stronger relationships. A participant (P8) described how she has a greater appreciation for her friends and significant others.

It’s made me appreciate my friends and my boyfriend and in a really crazy way because they were there for me the entire time, despite finals and their own family and personal stuff. . . . I think that because they saw what I was going through, it kind of allowed us to bond in a special way.

Participants realized who in their life was a true friend and then found that those friendships grew stronger. A participant (P3) described this as “It shows you what friends are really there for you and they will support you through the hard times too.” Another participant (P9) explained how this was a beneficial experience for her.
My friends, a lot of them stepped up. At the same time, you realize who your true friends are because you see the people that keep in touch and check on you but then there's people that don't. . . . There is some good that comes out of it because you realize who's going to be there for you when you need it.

*The effects of parental cancer on family life.* Almost all participants mentioned changes in their family dynamics since their parent was diagnosed with cancer. These changes included: dynamic and role changes, changing your view of your parent, bringing family closer, and prioritizing family. A participant (P2) discussed how her family came together to help their mom during her cancer treatment.

At the beginning, she held up pretty well and then it kind of got worse but I know everyone started chipping in a lot more. My mom had always been the one to take care of everything, make dinner and clean up and it just completely changed. My dad, he always did the maintenance stuff but he started doing domestic stuff. He became a lot more affectionate. I found it was a lot different from before. I found my sister who was very dependent on my parents completely changed. She took a lot more responsibility on and . . . I found she grew up a lot. My brother . . . he had Asperger [syndrome] and my parents did a lot to make him independent but my mom still babied him at home and he just blew me away. He just completely grew up . . . he just completely transformed.

Participants talked about how the role of their parent with cancer changed in their family. Often there was a loss of that parent’s role. A participant (P15) talked about how he had a different level of support from his mother than his sister did because of his mother’s cancer.
You don't have the same support back. When my sister started university, it was before my mom had her metastasized breast cancer, so my mom was really there for her . . . and you don't get that. You don't have as much of a parental influence or you don't have that backbone that I think some other kids have.

Another participant (P4) discussed how she was able to have her mom around but that her mom could not play the same role with her younger sisters as they grew up.

I grew up with a really secure stable family because my mom didn't get sick until I was 18 . . . until then everything was fine. For my sisters, they were in grade 7 and 8, when she was sick, and so they kind of went through those last couple of years of elementary school without her support. She was always sick and she stopped being able to come to their soccer games and things.

Some participants also discussed how their relationship with their parents changed because their parents began keeping certain information to themselves, to protect them and to not distract them from school. A participant (P5) discussed how her relationship with her parents changed when they began to keep information about her mother’s cancer away from her.

I think it affected my relationship with my parents just because they're hesitant to tell me things because I'm at school. My mom knew she had cancer two weeks before I found out . . . . I was about to go into exams so she didn't want to tell me. . . . They were doing it for the best . . . but . . . when you find out that they've been dealing with it for a couple of months and you had no idea, it just makes you feel even worse.
Participants also found that as their family life changed, so did their view of their parent. Participants talked about how they may have taken for granted their parents before, but now they had a new appreciation for them. A participant (P1) explained this as “I think it changes from you always being able to look up to your parents, know that they're going to be there for you, to realizing that you actually have to be there for them.” Another participant (P2) talked about how her perception of her mother changed from before the cancer to after.

I just find it really changes your outlook on life and towards family. Me and my mom had always been at odds. When you realize that you will lose your parent, you kind of see them in a different light, like they're not always going to be around. You see all the best parts of them.

The majority of participants found that their experience made their family grow closer. Participants talked about having a greater appreciator for their parent and entire family. A participant (P1) talked about how the loss of her dad’s invincibility made her appreciate him more.

Before, it was more okay to go a month without seeing them [parents] because I was busy but . . . time is more precious now and knowing that . . . life is not infinite. My dad is not invincible, so I need to actually make the time and effort to see him. Otherwise, one day I could have regrets.

Another participant (P15) talked about how families become closer and spend more time together when they go through something like cancer.
Anything like that, it brings your family a lot closer . . . it's a sobering thought. Your mom has cancer, so you see them [family] a lot more. You do a lot more family stuff. It used to always be a drag to you know “mom wants to go out to do family time” but now it's kind of . . . let's go do stuff. Immediate family, we're a lot tighter now, a lot more open with each other about stuff.

A participant (P17) talked about how her experience led to her always putting her family first.

In some ways, it's a good outcome. At this point, I always put my family first and everything I do, it's for my family. It always goes back to them and so that's why I think it's good. It keeps me in check. I don't blow up over little things and I know what really matters and just how close life is.

*Positive personal outcomes*. Participants discussed specific positive outcomes such as greater maturity, improved ability to relate to others, and a more positive and gracious outlook on life. Many participants mentioned feeling more mature but they also claimed their experience has made them grow up faster than their peers. A participant (P6) discussed how her level of maturity affects how her friends see her.

I have higher expectations of myself . . . I guess I'm just faster growing up, way faster, compared with my friends. . . . Even when I'm with my housemates, they will be like “Oh Jessica you're so thoughtful” . . . but I'll be like “Oh am I?” I'm just very used to it already so they just see me very differently.
Another participant (P15) explained how his experience with parental cancer has made him grow up and how it has made him feel different from his group of friends.

You grow up a lot faster. . . . I still like to have a lot of fun here and there but at the end of the day, I kind of realize that I might have to take a leading role in our immediate family pretty soon. . . . An example, all my buddies, all my roommates, just went to SnowJam [student ski vacation package] this week . . . and I got two jobs. You just keep paying for stuff and you're putting in funds. You're making money and stuff like that. You want to take on more responsibility.

Participants often commented on how they felt more capable of relating to other people, who were going through a similar experience as they were. Some participants talked about being more compassionate of others’ feelings in general. A participant (P10) described how her experience has made her more compassionate.

It made me more compassionate of what other people are going through. Not a lot of people know what’s going on in my life . . . I don’t know what's going on in someone else’s [life] so you just have to be nice to anyone you see.

Another participant talked about how his experience with having a parent with cancer has made him more compassionate to others who have lost a parent or who have a family member with cancer.

There was this one time. I got a phone call from my mom and I was driving home and she was saying “It's really bad. You have to come home now, otherwise he might not be alive tomorrow.” . . . So I've lived through an experience, where I thought my dad had
passed away, which is really messed up. So I can kind of relate to people who have felt that. . . . So now looking at individuals who have had that or who are fighting cancer with a family member, I can definitely relate.

Participants gained a more positive outlook on life after experiencing having a parent with cancer. Participants talked about feeling grateful for what they had in their life. A participant (P9) discussed how her perspective on life changed for the better.

It’s almost an epiphany on life now . . . a different perspective on what's really important and what's not. I used to get super stressed out about certain things like a test or little things. Now it's not even worth it . . . I've definitely learned to just “don't sweat the small stuff”.

Another participant talked about how she has learned to not take anything for granted in her life. I think just appreciating everything. . . . If you take things for granted, you never know how important that thing might be for you but if you just appreciate everything from the very beginning, you won't regret that much later on.

Participants talked about their gratefulness for the resources that were available for their parent and family, especially health resources. A participant (P13) talked about her experience and how grateful she is for how her dad’s cancer is being treated.

I have a new, not a new view of life, but it has definitely made me think differently. . . . I feel really fortunate that we have all these resources and a lot of support. . . . It could be a lot worse. Most people don't find out about pancreatic cancer until they're jaundice
because their liver has already failed. So just the fact that we found out about it . . . we have a head start.

Another participant (P8) discussed how her perspective on life changed after having seen both her grandmother and mother experience cancer.

I felt like I could either choose to be like my grandmother. In the face of all this stress and awful situations, I could be on top and strive and do the best that I possibly can and smile and have a good time. Or I could be like my mom, who was more like “feel sorry for me and help me and do things.” . . . I guess that sort of taught me how to deal with situations and hardships and how to make do with them.

**Influences on Life as a University Student**

When discussing how having a parent with cancer affected participants’ lives at school specifically, participants discussed the issue of distance from home, the desire to be home more, using university as a distraction, dread about university, high stress levels, having difficulty focussing on university work, finding motivation to do well in university, and adapting.

**Distance and desire to be home.** Participants described the distance between home and university as distressing. Many participants described having a stronger desire to go home to visit their family after they discovered that their parent had cancer. A participant (P7) discussed her concern about being at university and away from home.

I think I probably do worry a bit about the fact that I'm not at home and I can't help out as much. . . . I just kind of hope that, when I'm at home, I can help out as much as possible and then hopefully that'll be enough of a difference that it helps them over the week.
Participants discussed having a desire to help out at home and they identified the distance between their home and university as a barrier. A participant (P15) described his desire to be with his mom and help out his dad simultaneously.

I'm the same way as her. I want to spend as much time with her as she wants to with me. . . I always wanted to move back to Nova Scotia. That's where I was born and raised and I always wanted to go to Dalhousie [University]. That was my dream . . . that [parental cancer] is obviously going to change your life too, so now I go to [University of] Guelph instead of Dalhousie. Coming home every weekend . . . I want to do it . . . I don't want to say it's less for my mom but it's more to give my dad a break too. He's the only one around.

Another participant (P1) discussed what it was like to be away from home during her undergraduate degree and how things have changed since starting her master’s degree.

I think it definitely was different [living away from home during her undergraduate degree]. I still live away from home but now I'm only 10 minutes away instead of an hour away. While I was still in undergrad . . . I felt like I should be going home more often and I think there is still that sense of I need to keep on seeing my parents.

*Using university as a distraction.* Despite participants having a desire to be home, many participants commented on how they used school as a method of distracting themselves from their parent’s cancer. A participant (P4) described how near the end of her mother’s life, she used her schoolwork to distract herself.
At the time, I actually thought she was going be fine, until about a month before she died, because her friend told me that she wasn't [going to be fine]. She didn't tell us that she was dying. . . . That was while I was writing my final exams in second year but I just wrote them all and I think maybe I distracted myself with school. I look back and I'm like “how was I getting 90s at the time?” but I think maybe being in school was actually a good distraction for me.

A participant (P16) commented that, at times, he was “fortunate to be able to come back to school and almost block it out.” The same participant (P16) described how he used university to avoid thinking about his dad’s cancer, whereas his brother became consumed with their dad’s cancer.

I made myself so busy that I wasn't able to think about it because as soon as I thought about it, I wanted to be there and I realized that I couldn't be there because I had to be here going to class. I'd be writing midterms and handing in assignments. . . . I feel like in the future I could definitely be there more. I think that's a huge thing but . . . my brother was there the whole time and it consumed his life. He didn't really have a choice. He was taking care of him day-in and day-out 24/7 and that caused a lot of stress on him. So, given the circumstances, I didn't have that ability because I had to finish what I had started here at school.

*Dread and stress.* Participants described feeling more stressed at university because of their parent’s cancer. The stress that participants identified was usually caused by wanting to be home and not being able to, thinking about their parent’s cancer, and finding it difficult to focus.
Participants also talked about how the stress and anxiety that they were feeling because of their parent’s cancer affected their mental well-being. A participant (P11) described emotional breakdowns that occurred during university.

When I was going through it [parent’s cancer], I had periods of breakdown when I would stress out about school so much. So I'd be stressing out about school but then I'd take a step back and be like “Why am I stressing out about this? There are bigger fish to fry.”

Some participants discussed the dread that they felt about going to university and doing coursework. A participant (P2) described her experience of dread and how it affected how she felt about university.

I found going into second year, I dreaded it. I didn’t want to go back because at the point when I was going, they didn't know . . . they knew it was stage three but they didn't know if it was getting worse or if the treatment was working, so I didn't want to go back. I just remember second year . . . the first semester was just so stressful. I called home all the time, crying . . . I couldn't really care about what I was learning. I wanted to be back home.

Participants often talked about how their parent’s cancer became an ongoing stressor. Having their parent’s cancer in the back of their mind affected their mental well-being. A participant (P16) discussed how he became anxious, when his dad was diagnosed, and how he stayed anxious afterwards.

It became a constant stress . . . in the back of my subconscious . . . “What’s happening? How's he doing? What’s going to happen? Is he going to do radiation? Is the chemo
going to work?” . . . I feel like it made me kind of anxious . . . that still hasn't really left. I'm still a little anxious all the time, even now when he's cured.

**Difficulty staying focussed.** Participants commented on how the emotions that they were experiencing regarding their parent’s cancer often made it difficult to focus on university work. A participant (P16) described how the experience of parental cancer made it difficult to focus.

It's hard at first . . . you're in denial about it and you’re like “No, this can’t be happening to me. This isn't real.” and then it kind of sets in. It definitely affected my life. It affected my school and my ability to concentrate on work.

A participant (P1) compared the difference in the ability to focus among students who do not have health concerns in their family and students who do.

I think compared to students I know who don't have any significant health concerns in their family, it does distract you when you do think about your family. . . . It can be harder to stay mentally focused on a task especially if something happens like when my dad has an appointment in S------ every three months just to track how he's doing. Usually after he has those appointments, there's a period where it's hard to focus on schoolwork.

Participants mentioned that their parent’s cancer did not affect them as much as it did other days and so participants would go through cycles of being able to handle school one day and then not being able to handle it the next. A participant (P9) described this pattern as “It
definitely makes it difficult at times. It's really hard to focus. Some days, you can carry on and just think about it a little bit but be okay and some days, you just feel awful.”

Motivation to do well in university. Despite participants’ stress levels being high and having strong desires to be home, some participants found their experience with parental cancer to be a motivator for doing well in their academics. A participant (P9) described this as “I'm sure they [grades] would be even better if I wasn't in this situation, but at the same time, sometimes I think it drives me a little bit. It makes me want to do better.” For some participants, this motivation stemmed from their relationship with their parent. A participant (P12) described his motivation for doing well in university as “I guess my dad always had a commitment to his work so I've tried to be a better student and just be more committed to my studies and my academics.” Another participant (P17) discussed how her experience with parental cancer has changed her view of university.

It gives me a little more respect for what I'm doing here. I'm here to learn. I'm here to get my degree. I'm here to get everything out of this education. So you know the people who are out partying every night? I don't really want to do that, not because I can't, but just because I'm not here for that.

Adaptation. Participants discussed their struggles with having a parent with cancer and being a student but they also discussed how they adapted to this situation. Some participants adapted by changing their course load. A participant (P13) described how she changed her course load to help manage the stress that she was feeling.

So that was, I think, a good relief just to not have so many classes to worry about [lessened course load previously]. I only had one studio [art] so then it was less workload
that way and it has gotten easier. In the fall, I took a full course load and now I’m doing a
full course load so it's still a struggle. I'm juggling but . . . I think that term was the most
crucial time to take some extra time and now . . . it feels more normal functioning at a
full pace.

Many participants talked about accepting the situation and moving on with their life both
in university and in general. A participant (P15) described what adaption meant to him.
I just made . . . it sounds awful but it's not that bad. . . . You have your doubts and you
just live with it . . . you just adapt to the situation, see the bright side of it and you just
move on.

Also, participants discussed learning how to adapt to their parent having cancer. A participant
(P3) described how she progressed into accepting and adapting to the fact that her parent had
cancer, “I was a little worried about it [cancer] at the beginning but I think I've just kind of
learned to get past that.”

Coping with having a parent with cancer
We asked participants how they coped with having a parent with cancer and if there were any
specific strategies that they used. The identified strategies include communicating and visiting
with significant others, counselling, avoidance of the issue, focussing on normality, and
acceptance.

Communicating and visiting with significant others. Although some participants chose
not to share their feelings about having a parent with cancer with their significant others, many
participants found that communicating with people who are important to them was helpful for
coping with the emotions that came up regarding their parent’s illness. A participant (P9) described the importance of communicating with people in her life.

Talking with other people is the main thing . . . like when I'm upset, I don't just sit there and pout. I go to a roommate, call a friend from home, call my mom or talk to somebody. I think that's the biggest coping mechanism.

Another participant (P4) described how important it was for her to be able to communicate with her siblings and a grandparent.

It was really good to have my sisters. I felt really lucky to have three sisters that were going through the same things. I remember at the time thinking that if I was an only child, I don't know how I would deal with this because I had people to talk to who were going through it and you didn't have to hide anything from them. One grandmother, who I'm actually not close with at all, who's my mom's mom; we became kind of close at that time and she really came through so she was good to talk to.

Most participants identified spending more time and visiting with family as helpful coping mechanisms. They expressed a desire to visit home more often or at least to contact their family more often. A participant (P10) explained the importance of visiting with family by stating that “I go home a lot, and I like spending time with my family and talking to them at least three times on the phone.”

Counselling. Most participants did not seek out formal counselling, which is important to note considering the significant impact that having a parent with cancer can have on a person’s mental health and well-being. Only four participants had sought out formal support or were
planning to in the near future. There was discussion with these four participants on how
counselling seemed like it would be awkward or unnecessary at first. The four participants were
happy that they sought out counselling in the end. One of these four participants (P6) discussed
her current intentions to seek out counselling.

I don't know if it's too weird if I just make an appointment and sit down and talk about
my own stuff. I think that's how counseling works. I also find it a little awkward because
randomly opening up myself throws all my problems to the counselor but I feel it will be
useful for me just because I really need help.

Many participants discussed how support from family and friends was helpful enough for them
and consequently they did not need to seek out further counseling.

Avoidance and Normality. Despite participants finding it helpful to communicate their
feelings with significant others, they also mentioned trying to avoid thinking about their parent
having cancer. Many participants mentioned focussing on what was normal in their life and
avoiding what did not feel normal to them. For example, a participant (P13) explained how
focussing on the normal aspects of her family’s life helped her and her family cope.

I know my tendency is to kind of deal with things by removing or distancing myself. . . .
I think it's important for all of us to do our own things and move on with our lives and
not dwell on it so much, to not try to force affection. I would feel uncomfortable to go
home and be like “Hey, let's put on this show and spend all this quality family time.” For
me, it's just as nice to go home and hang out with my parents and treat it like it's any
other day.
Many participants discussed how being away at university, although difficult, was sometimes a way to avoid dealing with their parents’ cancer. A participant (P4) explained how university allowed her to avoid the reality of her parent’s cancer for a while.

She had just started going through chemo when I went and moved into residence in first year. So for first and second year, I wasn’t at home and I think living in the university bubble was one of my coping mechanisms because I could detach myself from everything that was happening and say everything is going to be fine. Then when I would go home on a weekend, I would realize it's not okay but I think that was probably a big part of how I dealt with it. At the time, I was just living my life separate from it.

Acceptance. Participants expressed that they accepted that their parent had cancer and that the best thing they could do was to just keep going and doing what was normal for them. A participant (P8) explained how she accepted her mother’s diagnosis.

I coped with that just by knowing that I'm helping her and knowing that she needed that and knowing that was really the only thing I could do because I can't change her diagnosis. I can't make it go away. I can only help her live each day and smile.

For some participants, there was more of a discussion of the acceptance that their parent may not recover and that they may die. A participant (P16) explained what it felt like to experience this.

There was definitely a time where I thought it’s over. He’s going downhill. There's no coming back here so . . . there's a point where you have to accept it almost and I mean it sounds terrible but you have to really accept that that's what's going to happen.
Attitudes and Experiences around Health and Personal Lifestyle

Participants were asked how their experience with parental cancer affected their health beliefs, feelings of susceptibility and health behaviours. Participants talked about becoming more health conscious, strong beliefs in cancer prevention, and having a healthier lifestyle. They talked about their own susceptibility to cancer and whether that had changed since their parent had cancer. Participants talked about their confidence to make behaviour changes or to maintain them. They also discussed how positive outcomes such as having more energy, feeling happier, and improving their health were motivators to making positive changes in their personal health behaviours. Participants explained how the university atmosphere, time and money constraints, likes and dislikes, and the influence of friends and family were challenges they faced, when trying to live a healthier lifestyle.

Becoming more health conscious. All participants identified being more health conscious since having experienced a parent having cancer. Participants discussed having an increased general awareness of how the lifestyle someone has now can affect them later on in life. A participant (P1) described her thoughts on how she has become more conscious of her health.

I think it has made me slightly more health conscious . . . understanding that what you do now does impact you down the road. So trying to live a generally healthy life will probably help prevent something or at least give you another couple of years before it's an issue.

Another participant (P6) elaborated on how experiencing having a parent with cancer has made her more involved in her personal health.
So I know I have to be really alert and aware of my own health. . . . I don't want cancer and nobody wants cancer. . . . If I already know I'm at that higher risk, then I'm more active and involved in my own health.

Although some participants talked about being more health conscious and involved in their own health, there were participants who hadn’t made significant changes in their lifestyle. A participant (P14) explained “I’m just more aware when I hear things about cancer in general. I know you should be protecting yourself. I can't say I've changed a whole lot about my health but I’m definitely more keen to listen.”

**Beliefs in cancer prevention.** Along with participants thinking that health is important in general, they often stated how important they felt being healthy was in the prevention of cancer. A participant (P8) discussed how she prioritizes her health in order to reduce her risk of developing cancer.

Stress is a huge part of university. . . . just to try and feel less stressed because university isn't as bad as cancer is. I'm really lucky to be here. . . . trying to eat healthy and workout. . . . just to minimize the likelihood and the severity of the cancer I hope to not have.

Another participant (P12) described how living a healthy lifestyle, being mindful, and seeking the help of health professionals were all important factors in reducing someone’s risk of getting cancer.

Eating as healthy as you can, getting exercise, just taking care of your body, and going to the doctor and getting check-ups. Just being mindful of the things that can happen to you
and being mindful of the things that you can do to sort of prevent them. I know cancer is something that you can catch and then deal with it and then sometimes it's “Oh, you have full-blown cancer and there's not much we can do about it.” So just being healthy in general and taking care of your body and then also realizing that you’re not the only one who can take care of your body. There are doctors out there and you have to seek them out. You have to make your own check-ups.

Occasionally, participants stated that they felt cancer is inevitable and that there is not much you can do to prevent it. A participant (P4) stated “At the same time, it sometimes feels inevitable and I think ‘why worry about it because it's going to get us’.” Another participant (P12) discussed the idea that cancer comes out of nowhere, “I think there’s really nothing you can do about it. I don't think there was anything my dad could have done to avoid getting thyroid cancer. Maybe there is but maybe there isn't.”

*Healthier lifestyle.* Many participants stated that they improved their lifestyle since their parent became diagnosed with cancer. They discussed changes in diet, physical activity, and stress management. Some participants did not make changes to their lifestyle, but most participants acknowledged the importance of having a healthier lifestyle. A participant (P10) described how her health behaviours have expanded since her father was diagnosed with cancer.

I just know what I'm eating. I make my own food now and I don't eat fast food. . . . I work out every day but I was doing that before so I haven’t made that many changes. I guess I just continued them and I’m more knowledgeable about what I actually have to do.
Another participant described how she altered her dietary habits after her dad was diagnosed with cancer.

From the dietary perspective . . . I guess this is where I buy in to some maybe not real science going on, things like the artificial sweeteners. I'm definitely more concerned about that than I ever was before even though I know the evidence isn't necessarily that strong in either direction and there's a lot of very conflicting evidence. I think I am slightly more concerned about all of the additives and things that we're putting into things . . . this is just another thing that comes up on my checklist when I'm looking at food. I probably wouldn't have gone for artificial sweeteners before but now I'm even less likely to.

Many participants mentioned being more active as well as making changes to their diet. A participant (P16) talked about how he has become more physically active and changed his diet.

I joined the squash league and I'm playing on my roommate’s basketball team as well. It's been really good to do that. I had quite a bit of injuries in the past so it's hard to jump back into sports but I’m trying to take it slow. I've been going to the gym a lot more and I'm really focusing more on my diet. Before, I'd eat out quite regularly and not only was it expensive but I don't think it was that healthy for me. I’ve been eating a lot of rice, a lot of whole foods, so I think that plays a large role in my health physically . . . I’m just trying to stay as healthy as possible. That's my goal.
The same participant (P16) also elaborated on how important mental health is, when he talked about work-life balance.

I think the hugest thing is work-life balance. Before, . . . I always thought I was going to hustle really hard when I was younger and I was going to work as hard as I could to get a senior position and then it would kind of you plateau at some point. Now I realize that if you don't take time to do things you love now, you're never going to do them. It's kind of hard to see that happen because you can work as hard as you want. You can try to take on the world but at the end of the day, if you're not able to actually do it all, it's going to mentally affect you and it's going to physically affect you, like what's happening to my stomach currently.

Some participants mentioned how their parent with cancer had made positive health changes and because of that, participants and their other family members were motivated to make changes as well. A participant (P2) described how her family followed her mom’s lifestyle changes.

My mom started completely changing her lifestyle and we kind of followed suit. I've come to realize, between my dad's genes and my mom's genes, I'm going to get something and the best way to stop that is just taking care of yourself. When I was younger, I ate anything and didn't really exercise unless it was a team or something, and now . . . health has become the most important thing in my family. My dad has lost a lot of weight. My brother runs every day and my sister does the same thing.

*Feelings of susceptibility.* Participants talked about how having a parent with cancer
made them think about their own susceptibility to cancer. A lot of participants, since seeing someone close to them go through cancer, were reminded that everyone is susceptible to cancer. A participant (5) talked about how cancer does not discriminate.

I think everyone is sort of naive and thinks that it's not going to happen to me . . . with the amount of people in my own family and friends that I've seen, it happens to everybody. It doesn't discriminate who it happens to. For some people, there are precursors . . . like my mom laying in the sun but then there are other ones that make no sense at all. I think . . . you need to be very aware and do anything you can to keep it from happening to you.

The majority of participants felt more susceptible to cancer after their parent was diagnosed with cancer. There was discussion about participants losing invincibility and wanting to do more to protect themselves. A participant (P1) stated “It's just the loss of the idea of invincibility. If this can happen to you [father], one day it could happen to me, so try to make the best decisions that prevent that from happening.” Another participant (P11) said “I feel more susceptible, especially with it being progressive with my grandma and then my mom and then it's ‘oh I'm next’.” Another participant (P8) talked about how experiencing parental cancer has made her appreciate life more while simultaneously making her feel scared of getting cancer.

It's not just a word to me, there's so much more to it. I definitely have been scared into doing the right things for myself so that I hopefully don't get it [cancer] or can come out of it alive. I think for anybody who has a parent or a close relative with cancer or even just a really serious illness, it makes you appreciate life but also appreciate it in a way
where you want to conserve your life and not do stupid things to change your life dramatically in a negative way.

Some participants talked about not feeling more susceptible as well. A participant (P12) stated “If I went my whole life and I didn't get thyroid cancer, I wouldn't be surprised. I'm not expecting to get it.” Some participants believed that no one had control over whether they would get cancer. A participant (P9) commented on this belief “I think that you only have so much control over it . . . I wouldn't think because my dad had it that I have a bigger chance of getting it.” Another theme that was addressed was the idea of not feeling susceptible because participants felt that they had already had to deal with the difficult situation of having a parent with cancer. A participant (P15) discussed his feelings.

You almost feel like life couldn't give you anything right after that happens to someone that you love so much, that’s so important in your life . . . why would this ever happen twice? You’re conscious about it so I get checks . . . I don’t feel any more susceptible than anybody else.

Self-efficacy. Participants demonstrated confidence in their ability to live a healthier lifestyle or to maintain the positive habits they currently have. Participants talked about feeling confident in their ability to make lifelong habits. A participant (P8) stated “It's really hard to maintain a really healthy lifestyle at school but I think that if I am capable of doing that here, then I'm capable of doing it at any other time.” A participant (P10) commented on the changes that she has made and how she thinks they are sustainable.
I've definitely gotten into a routine. I like scheduling. My dad and I prep my meals on Sunday, so I do that and I plan out when I'm going to go to the gym . . . I know I'll bring that into my work life or my family life when I get older.

Participants talked about how they had already made changes and because they are young, they feel that establishing habits now will make it easier in the long run. A participant (P16) discussed how he feels motivated making positive changes in his life.

I believe I can . . . I think if if you want something bad enough, then you make it a priority. You're going to be able to do it. So if you want to play sports in the future or if you want to eat healthy, you need to make time for it. Obviously you're going to have to sacrifice something else but what's most important is your health and sanity. I think realistically it is sustainable and I've been doing most of this for three months now. I feel like it's been going well. I don’t feel any desire to stop doing it.

Motivation associated with positive outcomes for behaviour changes. Participants were motivated to make positive health behaviour changes because of the positive outcome expectations for those behaviours. Some of those outcomes included reducing cancer risk, feeling good, and having more energy. A participant (P6) said “For choosing healthy foods, it's good for my health and it will probably lower my risk of getting cancer, which is awesome.” Another participant (P10) decided to do yoga and she explained this decision as, “I like the mind-body connection . . . it’s also just peaceful. I could wake up for a 6:30 yoga class because it's not too much . . . it's just calming and I feel good after.” Another participant (P12) mentioned how not worrying later was a motivator for making healthy choices now, “Just peace of mind
and just knowing that the more conscious you are of it in the present, the less you'll have to worry about it later. The less you'll have to undo later.”

Participants often talked about having more energy and feeling better, especially if they had become more active and had started eating better. Many identified physical activity as a good stress reliever as well. A participant (P16) talked about the benefits he received from making positive health changes.

I have more energy. There's obviously a time when you get down and you get low but I find going to the gym regularly helps me maintain more of a stable mentality and a stable personality. My emotions are very on par because it gives you more energy. You feel better about yourself. You feel more awake. Plus, when you spend a lot of money on food and things like that, you’re always worrying about money and so now I go to the grocery store every Tuesday [student day]. I make sure that I pack my lunches and things like that . . . not only is it helping me financially and mentally but physically. The nutrients are helping me a lot. Whole foods are really good for you. I make sure that I eat as healthy as possible. You physically notice a difference when you're eating healthy foods in comparison to pizza and junk.

Challenges to making behaviour changes. Although participants seemed highly motivated overall, certain barriers were discussed. These barriers included the university atmosphere, time and money constraints, likes and dislikes, and the influence of friends and family. A participant (P8) described the university atmosphere as:
The university atmosphere, it's a barrier in itself because you know you have finals. You're pulling all-nighters. You're drinking a ton of coffee and you're eating crap because it's right there. It's really hard to maintain a really healthy lifestyle at school.

Another participant (P15) described what many participants faced, which was the difficulty in finding balance between university demands and taking care of your personal well-being.

It’s less about physical health. Working out is a great way to deal with this stuff too, so you try to get to the gym as much as you can but you just don't feel like it. And when you do want to go to the gym, you can’t because you just feel like ‘There's all this stuff I have to do. This isn't important. Who cares about going to the gym? You'll be fine. Just go do your schoolwork and get home.’ In that sense, you put other stuff in front of what your health should be.

Along with a challenging university environment, participants commented on the constraints that they had when it came to money and time. A participant (P6) described her situation and how she feels somewhat helpless when it comes to her financial constraints specifically.

Time and money. University students don't really have much time to do whatever they want and I don't really have the money to sign up for a lot of fitness classes at the gym. They’ll be pretty useful because it forces you to actually exercise and actually move around just because you paid for those classes but I just can't really afford those. I can always cut back on other expenses and use that money for activity-related courses but it's just not very feasible in my case.
Another participant (P16) talked about time constraints and the challenges he faces.

There’s definitely the concept of time and how long everything takes. So it's about an hour and a half, if you want to go to the gym, including walking there, and this and that, showering, sauna, everything. So there's that and then there's making sure that you can. It's almost more scheduled, so your flexibility is kind of decreased and obviously your time with your friends isn't as consistent because you kind of have a lot of things. I schedule a lot of things and how I want to do it and that's how you get it done . . . It's tough. It's definitely hard but if you want it, if you make it a priority, you're going to be able to do it.

For some participants, their likes and dislikes strongly influenced making changes in their lifestyle. A participant (P4) stated “I almost just think it's a personality thing for me because I don't really like sports so I have to make a conscious effort to do things like swimming and yoga and things like that.” Another participant (P1) commented on how she dislikes physical activity so it does not become a priority.

I don't find physical activity in general particularly fun so it's something that, with everything else going on in life with family and school and a social life, it just ends up always being on the bottom of my list of priorities. I think I partially justify that by being fairly healthy in every other dimension so it's like doing one thing not particularly well is probably okay.
Participants also identified their friends and family as having a strong influence on the lifestyle choices that they make. Participants discussed how they affect food choices and habits and physical activity. A participant (P4) commented on how her social life affects what she eats sometimes: “Eating, your social life affects that because you go out to eat with people and stuff. Who you're dating or who you're living with at the time has definitely affected my eating patterns.” Another participant (P2) discussed how she feels she cannot eat what her friends eat all the time because she is trying to eat healthy and they are not.

Going out with friends . . . I don't have the same diets as they do. My one roommate can eat anything, she just doesn't really care so you go out with them and they get pizza at the end of the night and I'm like “Uh I can’t really do that.”

Discussion

In this study, we explored the experience of having a parent with cancer, when you are a young adult enrolled in university. This study gave a holistic view of the perceived outcomes of having a parent with cancer and how it affected participants’ personal lives and their lives as university students especially. This study also examined how this experience influenced participants’ health beliefs and behaviours in regards to cancer and their personal health.

To summarize the findings, participants identified environmental, genetic and lifestyle factors as potential risk factors for cancer. An unhealthy diet, physical inactivity, and stress levels were identified as key risk factors in participants’ parents. Participants believed that living a healthier lifestyle in general was the most effective way to prevent cancer and they believed that cancer is concerning because of the negative effects it has on the person who has cancer and his or her family. Participants experienced emotional turmoil during their experience, which
affected their friendships, relationships, and family. Despite challenges with friends understanding and family dynamic changes, many participants discussed having stronger relationships with friends and family. Participants also found that they developed a different and more positive life outlook after experiencing parental cancer.

When examining the influence that this experience had on participants’ lives at university, they discussed the issue of being far away from home. Many participants felt preoccupied and stressed because of this distance and the limited ability to go home. Some participants, who were closer to home, still desired to be home more and often spoke of how they visit home more now that their parent has or has had cancer. Participants spoke about the stress that they feel at school, which was linked to thinking about their parent having cancer and simultaneously wanting to be home. Occasionally, participants mentioned feeling guilty about being away from their parent. The stress and emotional turmoil that participants often felt hindered their ability to focus on their schoolwork and participants compared the situation before their parent had cancer and now. At the same time, some participants found that their parent having cancer motivated them to do well in school. Some participants described this motivation as being linked to making their parent proud or having a deeper respect for education itself. Participants also described school as a distraction. Many participants said they dove into their schoolwork as a means of coping with their parent’s cancer. Participants also discussed adapting to the stress and emotions that they were feeling and becoming stronger because of it. They discussed how they had good and bad days trying to cope with their parent’s cancer and they learned to work through that.

Participants identified that communicating with important people in their life helped them cope with their parent’s cancer. Participants relied on their family the most and then friends and
significant others. They also found that keeping some information to themselves was effective and many participants talked about trying to not think about their parent’s cancer at all. Focussing on what was still normal in their life was what many participants chose to do to cope. Few participants sought out formal counselling but those participants who did found it to be very helpful for both their personal and family life.

The majority of participants became more health conscious, made healthy lifestyle changes, and had strong beliefs in cancer prevention. Some participants did not make significant changes and that was usually because of the barriers such as the university atmosphere, their friends’ or family’s influence, their beliefs around their own susceptibility, or even just their likes and dislikes. Most participants felt confident that they could make changes in the future. For the participants who had already made changes, they felt especially confident because they had been able to make those changes while also being a student. This made them feel that their changes could be sustainable in the real world. Participants also discussed how positive outcomes such as having more energy, feeling happier, and improving their health were motivators to making positive changes in their personal health behaviours.

When discussing what participants thought caused cancer, participants were very knowledgeable of how lifestyle can play a role. Conversely, participants did not believe that lifestyle played a significant role in the development of their parent’s cancer specifically. Participants were aware of the role of smoking and physical inactivity. People’s weight status and how that could increase their risk of developing cancer was not a risk factor that participants identified in this study. Most participants thought that having a healthier diet could play a role in the prevention of cancer but few participants specifically elaborated that this diet should include
sufficient fruit and vegetables. However, some participants commented on how someone could eat less convenience foods and red meat.

Our results regarding how participants coped with their parent’s cancer coincides with previous research findings. Compas, Worsham, Ey, and Howell (1996) examined the coping strategies used by preadolescents, adolescents, and young adults who had a parent with cancer. Similar to our results, they found that participants often used emotion-focused coping by avoiding or attempting to be distracted from their parent’s cancer or the feelings they were experiencing because of their parent’s cancer. Our study supports this point as our participants were young adults and the majority of them used emotion-focused coping strategies. Our participants also used coping strategies such as communicating and spending more time with family and friends.

Participants in our study were asked to describe the outcomes of having a parent with cancer. Our findings related to both positive and negative friendship changes, family dynamic changes, and personal positive outcomes tend to align with previous research results. Patterson and Rangganadhan (2010) examined the needs of both adolescents and young adults who had a parent die of cancer. These adolescents and young adults identified “support and understanding” as their most prevalent unmet need. The participants mentioned needing more support from their teachers, friends, the general public, and their own family members. Friends were identified as being unable to have a full understanding of the experience of losing a parent to cancer and how this experience affected the bereaved adolescent or young adult was discussed (Patterson & Rangganadhan, 2010). In our study, a lack of support was not identified as an issue directly and most participants expressed receiving support from certain friends, their family and school administration and teachers. However, some participants did report that some of their friendships
ended or were strained because those friends could not understand what the participant was going through. Participants discussed withdrawing socially, despite the support that they were receiving. Participants also reported prioritizing time with their family over time with their friends. These findings of social withdrawal and prioritization of the family are in line with the findings of Schmidt and Welsh (2010) who found that participants withdrew socially and also felt strain in their friendships because there was not enough time to spend with both friends and family.

Leedham and Meyerowitz (1999) examined the experiences of parental cancer from the perspective of adult women who lost a parent to cancer during their childhood. These adult offspring who experienced parental cancer in their youth were affected psychologically because they had to face short-term effects of cancer in the family including: changes in family members’ roles, less quality time with their parent with cancer, their parent being debilitated by their illness, having to take on more household responsibilities, and the financial strain on the family. Our study yielded very similar results with the exception of household responsibilities, as most of our participants were living away from home at the time that their parent had cancer. Also, participants in our study did not report financial strain as an outcome of having a parent with cancer.

Previous research has found that cancer patients’ spouses experience personal growth from being involved in the cancer experience and so can their offspring (Patterson & Rangganadhan, 2010). Levesque and Maybery (2012) found that adult offspring of people with cancer experience positive outcomes such as changing the relationship with their sick parent, the importance of family, altering their life priorities, and personal development. Participants in our study expressed similar positive outcomes. Another study found that offspring experienced
increased levels of compassion (Leedham & Meyerowitz, 1999). Similarly, our participants reported having increased compassion and being able to more easily relate to others who are experiencing cancer. Participants identified being closer to their sick parent and their family in general, similar to Leedham and Meyerowitz’s (1999) finding that offspring became closer with friends and family and also expressed being more appreciative. Leedham and Meyerowitz (1999) and Levesque and Maybery (2012) found that offspring became stronger, and similarly, participants in our study expressed feeling more mature and stronger because of their experience. Our participants also talked about how their parent’s illness led to discovering who their true friends are and thus ending relationships that may have not been best for them.

We also examined how the experience of parental cancer affected participants’ lives at school. There has been little previous research on how a serious illness like cancer affects students. Leedham and Meyerowitz (1999) found that participants reported that they had difficulties with schooling. Schmidt and Welsh (2010) explored how facing the chronic and/or terminal illness of a family member affects university students’ adjustment to university life. Schmidt and Welsh (2010) examined social, academic and personal adjustment issues and benefits. Some students said that they became more motivated to do well in their schooling but that they also had more difficulties concentrating on their schoolwork. Students also found it challenging to find time to spend with their ill family member at home and to devote time to their assignments (Schmidt & Welsh, 2010). Participants in our study, who were all university students, had very similar outcomes except that our participants also discussed how they used school as a distraction to cope with their parent having cancer. Also, our participants elaborated on the stress that school causes them and how they feel dread about returning to school or doing schoolwork. Participants in our study also discussed how they desired to be home and how they
felt they were distanced from their parent because of their life at university. Participants in our study discussed adapting to the stresses of school while also dealing with having a parent with cancer. They often described feeling that they were able to handle the stress better as time went on, whereas in the beginning they felt they had not adapted yet.

Further, we explored how the experience of parental cancer influenced participants’ own health and health beliefs. Leedham and Meyerowitz (1999) found that participants discussed long-term changes that had occurred because of their parental cancer experience. These changes included increased awareness and understanding of cancer and altered views of health, death, and problems with their own physical health during their parent’s illness. Our participants had an increased awareness about cancer and altered views about health and the importance of health, but for the most part, they did not discuss altered views of death or problems with their own health. Some of our participants had health issues in regards to stress, and one participant described physical symptoms stemming from this stress. Levesque and Maybery (2012) found that participants reported becoming more aware of their own risk of developing cancer and which prevention measures they could take to reduce their risk. In terms of the latter, these participants identified sun protection, the need for regular medical appointments and their personal medicine usage, and the importance of diet. In our study, participants commented on becoming more health conscious and having a healthier lifestyle. A healthier lifestyle was usually elaborated on to include being more physically active, having a healthy diet, and managing stress. We also discussed participants’ feelings of susceptibility to cancer. Most participants felt that they were more susceptible but there were some participants who did not believe that their risk was any higher. Some participants also believed that cancer is somewhat inevitable for them. To expand on previous research, we discussed participants’ self-efficacy for
making behaviour changes, what motivates them to be healthy, and which barriers they face. Almost all participants reported being confident that they could make changes or maintain their current behaviours. This was often in connection to the health awareness that they had incurred because of their parent’s cancer. Participants discussed having more energy, feeling happier, and improving their health as motivators to making positive changes in their personal health behaviours. They explained how the university atmosphere, their personalities, and the stress of time and money were challenges that they faced when trying to live a healthier lifestyle.

When interpreting the results of this study, it is important to note that the first author, who interviewed participants, had personal experience with parental cancer. Although participants were not explicitly told this, it was obvious that participants assumed that the researcher had personal experience with parental cancer. It was obvious because participants mentioned that part of the reason they were participating in the study was to talk to someone who had been through a similar experience. After the interviews were over, many participants expressed feeling comfortable talking to someone who had been through a similar experience but who was also a stranger. We believe that this interviewer-interviewee connection may have been helpful in allowing participants to be honest and open about their experience.

Our study reaffirmed some of the conclusions from other studies but in a sample of participants who were young adults and also university students. Though our study found that participants were fairly knowledgeable about the possible causes of cancer, there is more education needed around which aspects of lifestyle can be changed to reduce someone’s risk of developing cancer. Many participants knew that being healthier would help but could not always identify specific strategies. However, participants were aware of the impact that physical activity can have in cancer prevention. Although a stressful lifestyle has not been strongly linked to
cancer (Canadian Cancer Society, 2013), many participants thought that stress had played a role in their parent’s cancer and that it has a significant effect on people’s health in general. Consistent with other research (Compas et al., 1996), our participants used less effective coping strategies such as trying to avoid what is bothering them or trying to distract themselves. Also, many participants did not think counseling was necessary. Some participants expressed feeling awkward about seeking counseling. This is concerning because of the impact that having a parent with cancer can have on a person. Participants in our study discussed similar outcomes that were mentioned in previous research (Levesque & Maybery, 2012) but they also discussed new topics such as communicating and visiting with friends and family to cope with their parent’s cancer, the dread and stress they felt around schooling, and using school as a distraction to cope. Our study expanded on the influence that having a parent with cancer can have on someone’s health. Almost all participants were more health conscious during and after their experience with parental cancer and most participants described losing their own sense of invincibility. It is important to note that some participants did not feel more susceptible and thus had not made significant changes to their lifestyle, despite being more health conscious in general.

Many participants were highly motivated and confident in adopting a healthy lifestyle due to their parent’s cancer but there were significant barriers identified across almost all of the interviews. Time, money, and the university atmosphere are the most modifiable barriers to these students living a healthier lifestyle. The workload in university takes up a large portion of most students’ time, but for our participants in particular, there was also the time involved in handling the stress and other emotions that they felt as their parent experienced cancer. The cost of university plays a large role in why students stated that money is an issue as well for purchasing
healthier foods or being more physically active. Many participants identified the cost of gym memberships as a barrier but it is important to note that there are ways to be active for free such as active transportation or recreational physical activity outdoors and participants did not discuss these forms of physical activity. The university atmosphere was described as a barrier because of the access to unhealthy foods and their lower cost in comparison to healthier foods. The university atmosphere was also described as a barrier because participants thought that it made it acceptable to be stressed, to work late into the night, and to prioritize school above other things such as their health.

**Strengths and Limitations**

A strength of this study was that it was theory driven. The interview guide was created using two health behavior theories and one coping theory. The theories identified a variety of constructs, which were helpful in the creation of the interview guide and in the interpretation of the data. These theories were used to help the researchers understand and explain the participants’ experiences as accurately and as thoroughly as possible. The first author’s use of memo-writing also allowed for a greater understanding of participants’ experiences and a more accurate recall of the interviews. Having the first and third author independently analyze all of the transcriptions strengthened the analysis in this study. By independently analyzing the transcripts and then meeting to discuss each other’s analysis, multiple interpretations and viewpoints were included in the analysis. The analysis was also more thorough because of this collaboration. The use of a paradigm was also a strength because it allows for the researchers to be open about their view of the world and how that influences their analysis of qualitative data. Though our sample of 17 was small, we felt that data saturation was reached. This small sample size allowed the first author to make a connection with individual participants. This connection allowed for the first
author to engage in an in-depth discussion of participants’ experiences with parental cancer and then to recall the interview when analyzing its transcription.

Although using interviews allowed for in-depth discussion, a limitation of doing interviews is that the participants may not feel comfortable disclosing detailed information about their experience in person. However, the first author aimed to build rapport at the beginning of the interview to try and overcome this limitation. Another limitation relates to the sample of participants. Even though the purpose of this study was to further examine the experience of parental cancer in young adult, university students, rather than achieving highly generalizable results, the sample of participants was homogeneous. This could be a limitation because the lived experiences we heard were those of Caucasian university students who were all, except for one, attending the same university. There were also only three men who participated in this study and so the experiences of young adult men were underrepresented. The eligibility criteria for this study created a limitation. Participants, who had experienced bereavement in the past six months, were exempted from participating. Although there may have been important information to discover while examining participants’ perceptions when they had recently experienced having and losing a parent with cancer, it would not have been fair to the participants to engage them during a time of grieving (Levesque & Maybery, 2012).

**Suggestions for Future Research**

In future research, it would be beneficial to seek out the experiences of people from other universities and other post-secondary institutions. It would also be important to examine the experiences of people from a variety of cultures and backgrounds. Also, longitudinal research could be done to examine whether the perceived outcomes of having a parent with cancer change over time and whether participants’ health beliefs and behaviours change over time. Future
research could also include quantitative measures for physical activity levels and other health factors to complement qualitative data collected.

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Declaration of Conflicting Interests

The author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article

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## Appendix A

### Interview Guide Questions and Prompts for Corresponding Research Objectives and Theoretical Constructs

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<th>Research objective</th>
<th>Question</th>
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<th>Theoretical construct</th>
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| (a) To examine young adult, university students’ perceptions and beliefs about cancer, its causes, and prevention strategies. | Introductions                                                            | Need to determine:  
- What kind of cancer did/does parent have?  
- What treatment did/do they receive?  
- What is your opinion on the overall care your parent received?  
- Is/was their parent in the home? If so, who is the primary caregiver?  
- Who are your immediate family members? | Perceived severity |
<p>|                                                                                  | Tell me a little bit about yourself and what brought you to this study today. |                                                                                                                                                | Subjective norms               |
| (a1) OK, now I’d like to discuss your thoughts on cancer itself. What do you think causes cancer? | (a1i) Do you think cancer is something to be concerned about? Why or why not? |                                                                                                                                                |                               |
|                                                                                  | (a1ii) Can you explain to me how you came to know what the causes of cancer were (society, family, friends)? |                                                                                                                                                |                               |
| (a2) Sometimes people talk about ways to reduce their cancer risk.                 | (a1i) Can you describe to me any prevention strategies that you                   |                                                                                                                                                |                               |</p>
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<td>(a) To examine the risk of developing cancer. Have you heard of any ways that people can prevent cancer? If so, which ones are effective and which ones aren’t? (a1) Now that we’ve talked about cancer, I’d like to discuss your parent’s cancer diagnosis specifically. What do you think caused your parent’s cancer, and why?</td>
<td>know of?</td>
<td>Cues to action</td>
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<td>(b) To examine these students’ perceived outcomes of their lived experience with parental cancer. (b1) We’ve discussed your parent’s cancer and now I would like to discuss how the experience of having a parent with cancer has affected your life. In your opinion, what are the effects on your relationship, family, and mental health? (b1ii) Some people have found</td>
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<td>outcomes of having a parent with cancer?</td>
<td>positive outcomes from their experience with parental cancer. Have you experienced any positive outcomes from your experience? If so, can you describe these outcomes?</td>
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<tr>
<td>(c) To examine these students’ coping strategies and support systems used during their experience of parental cancer.</td>
<td>(c1) Now that we’ve talked about the outcomes of your experience with a parent having cancer, I’d like to discuss how you coped/cope with your parent’s cancer. Can you describe to me, how you cope/coped with your parent’s cancer?</td>
<td>(c1i) Can you identify any specific activities or strategies that you use/used to cope with your parent’s cancer? If so, can you explain why you choose/chose those activities and strategies?</td>
<td>Coping / cognitive appraisal</td>
</tr>
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<td></td>
<td>(c2) What kinds of support do/did you and your family receive during this experience?</td>
<td>(c2ii) Do/did you seek out any support for yourself? If so, why did you seek out this form of support? (c2iii) Was/is this support you received effective for you? Why or why not?</td>
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<td>(d) To examine the influence of these students’ experiences with parental cancer on their life as a university student.</td>
<td>(d1) Now I’d like to discuss how this experience relates to your life here at university. In your opinion, how does/did your experience with parental</td>
<td>(d1i) How did/does it influence your social life? Your relationships and friendships? Can you explain why it affected your social life in this way?</td>
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<td>(e) To examine these students’ personal health beliefs and behaviours since experiencing parental cancer.</td>
<td>cancer influence your life at school?</td>
<td>(e2i) How did/does it influence your academic life? Can you explain why it influenced your academics?</td>
<td>Perceived susceptibility</td>
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<td>(e1) Lastly, I would like to discuss how the experience of having a parent with cancer has affected your personal health. How do you believe the experience has affected your health beliefs?</td>
<td>(e1i) Have your personal beliefs about your susceptibility to cancer changed? Why or why not?</td>
<td>Attitudes</td>
<td>Cues to action</td>
</tr>
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<td>(e2) Have you changed any of your behaviours due to your parent’s illness?</td>
<td>(e2i) If yes: Are you confident that you can maintain this/these behaviour change(s)? - If yes, why? - If no, why not?</td>
<td>Self-efficacy</td>
<td>Perceived behavioural control</td>
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<td>(e2ii) What benefits do you receive from making that/those health behaviour change(s) and what barriers do you face?</td>
<td>Perceived benefits and perceived barriers</td>
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<td>(e2iii) If no: Are you confident that you could make health behaviour changes? -If yes, why? -If no, why not?</td>
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<td>(e2iv) Is there anything that keeps</td>
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<td>you from making changes or makes those changes more difficult?</td>
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Research Study:

The Experience of Having a Parent with Cancer

Are you eligible?

Are you 18-29 years of age?

Are you a university or post-secondary student?

Has your parent had cancer while you were between the ages of 18 and 29?

1 hour interview

$20 for participating

Contact:
519-731-2167
cmcphail@uoguelph.ca

We’d love to meet you and hear your story.

Department of Family Relations & Applied Nutrition
7.2 Appendix B: Demographics Questionnaire

*Questions are based on the 2011 National Household Survey Questions (Statistics Canada, 2012)

Demographic Questionnaire

Participant #___________ Pseudonym:___________

1. What is your age? _________________ years.*

2. What is your sex?*
   - Male*
   - Female*
   - Other
   - Decline

3. Where were you born?*

   Born in Canada
   - Newfoundland/Labrador
   - Prince Edward Island
   - Nova Scotia
   - New Brunswick
   - Quebec
   - Ontario
   - Manitoba
   - Saskatchewan
   - Alberta
   - British Columbia
   - Yukon
   - Northwest Territories
   - Nunavut

   Born outside Canada: Please specify country
   ________________________________

4. Which of the following BEST describes your ethnic background? Please mark more than one if applicable or specify other ethnic background.

   - Aboriginal (First Nations, Métis, Inuit)*
- White
- South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc.)
- Chinese
- Black
- Filipino
- Latin American
- Arab
- Southeast Asian (e.g., Vietnamese, Cambodian, Malaysian, Laotian, etc.)
- West Asian (e.g., Iranian, Afghan, etc.)
- Korean
- Japanese
- Other – Please Specify

5. Which of the following best describes your HIGHEST level of education? Please mark more than one if applicable.

- Secondary (high) school Diploma or Certificate*
- Registered Apprenticeship or trades certificate or diploma
- College, CEGEP or other non-university certificate or diploma
- University certificate, diploma or degree
- Other- Please Specify
### 7.3 Appendix C: Interview Guide

Interview Guide Questions and Prompts for Corresponding Research Objectives and Theoretical Constructs

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<tr>
<td>(f) To examine young adult, university students’ perceptions and beliefs about cancer, its causes, and prevention strategies.</td>
<td>Introductions</td>
<td>Need to determine:</td>
<td>Perceived severity</td>
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|                                                                                   | Tell me a little bit about yourself and what brought you to this study today. | - What kind of cancer did/does parent had/have?  
- What treatment did/do they receive?  
- What is your opinion on the overall care your parent received?  
- Is/was their parent in the home? If so, who is the primary caregiver?  
- Who are your immediate family members? |
<p>| (b1) OK, now I’d like to discuss your thoughts on cancer itself. What do you think causes cancer? | (b1i) Do you think cancer is something to be concerned about? Why or why not? |                                                                                                                                                                                                        | Subjective norms              |
|                                                                                   | (b1ii) Can you explain to me how you came to know what the causes of cancer were (society, family, friends)? |                                                                                                                                                                                                        |                               |
| (b2) Sometimes people talk about ways to reduce their need to determine:           | (d1i) Can you describe to me any prevention strategies that you             |                                                                                                                                                                                                        |                               |</p>
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<tr>
<th>Research objective</th>
<th>Question</th>
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<tr>
<td></td>
<td>risk of developing cancer. Have you heard of any ways that people can prevent cancer? If so, which ones are effective and which ones aren’t?</td>
<td>know of?</td>
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<tr>
<td>(d1)</td>
<td>Now that we’ve talked about cancer, I’d like to discuss your parent’s cancer diagnosis specifically. What do you think caused your parent’s cancer, and why?</td>
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<tr>
<td>(g) To examine these students’ perceived outcomes of their lived experience with parental cancer.</td>
<td>We’ve discussed your parent’s cancer and now I would like to discuss how the experience of having a parent with cancer has affected your life. In your opinion, what are the</td>
<td>What were/are its effects on your • relationships • family • mental health</td>
<td>Cues to action</td>
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<tr>
<td>(e1)</td>
<td>(c1i) Some people have found</td>
<td>(c1ii)</td>
<td></td>
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<th>Research objective</th>
<th>Question</th>
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<tr>
<td>outcomes of having a parent with cancer?</td>
<td>positive outcomes from their experience with parental cancer. Have you experienced any positive outcomes from your experience? If so, can you describe these outcomes?</td>
<td>Coping / cognitive appraisal</td>
<td></td>
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<tr>
<td>(h) To examine these students’ coping strategies and support systems used during their experience of parental cancer.</td>
<td>Now that we’ve talked about the outcomes of your experience with a parent having cancer, I’d like to discuss how you coped/cope with your parent’s cancer. Can you describe to me, how you cope/coped with your parent’s cancer?</td>
<td>(f1i) Can you identify any specific activities or strategies that you use/used to cope with your parent’s cancer? If so, can you explain why you choose/chose those activities and strategies?</td>
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<td></td>
<td>What kinds of support do/did you and your family receive during this experience?</td>
<td>(d2i) Do/did you seek out any support for yourself? If so, why did you seek out this form of support? (d2iii) Was/is this support you received effective for you? Why or why not?</td>
<td></td>
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<tr>
<td>(i) To examine the influence of these students’ experiences with parental cancer on their life as a university student.</td>
<td>Now I’d like to discuss how this experience relates to your life here at university. In your opinion, how does/did your experience with parental</td>
<td>(e1i) How did/does it influence your social life? Your relationships and friendships? Can you explain why it affected your social life in this way?</td>
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<td>Research objective</td>
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<td>(j)</td>
<td>To examine these students’ personal health beliefs and behaviours since experiencing parental cancer.</td>
<td>(e2ii) How did/does it influence your academic life? Can you explain why it influenced your academics?</td>
<td>Perceived susceptibility</td>
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<td></td>
<td></td>
<td>(f1i) Have your personal beliefs about your susceptibility to cancer changed? Why or why not?</td>
<td>Attitudes</td>
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<td></td>
<td></td>
<td>(f2i) If yes: Are you confident that you can maintain this/these behaviour change(s)?</td>
<td>Cues to action</td>
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<td>- If yes, why?</td>
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<td>- If no, why not?</td>
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|                    |                                                                          | (f2ii) If no: Are you confident that you could make health behaviour changes?  
- If yes, why?  
- If no, why not?       | Self-efficacy                                           |
|                    |                                                                          | (f2iii) If no: Are you confident that you could make health behaviour changes?  
- If yes, why?  
- If no, why not?       | Perceived behavioural control                              |
<p>|                    |                                                                          | (f2iv) Is there anything that keeps                         | Perceived benefits and perceived barriers |
|                    |                                                                          | your parent’s illness?                                     |                                        |
|                    |                                                                          | (g1) Lastly, I would like to discuss how the experience of having a parent with cancer has affected your personal health. How do you believe the experience has affected your health beliefs? |                                        |
|                    |                                                                          | ipv1) Have you changed any of your behaviours due to your parent’s illness?                                  |                                        |</p>
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<th>Research objective</th>
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<td></td>
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<td>you from making changes or makes those changes more difficult?</td>
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7.4 Appendix D: Resources List for Participants

Resources

For University of Guelph Students ONLY:

University of Guelph Counselling Services
Telephone: 519-824-4120, extension 53244.

University of Guelph Student Health Services
Telephone: 519-824-4120, extension 52131.

For Both University of Guelph Students and Residents of Guelph (Non-Students):

Trellis Mental Health and Developmental Services
Telephone: 519-821-2060
Address: 147 Delhi Street, Guelph, ON N1E 4J3
Website: www.trellis.on.ca

Community Torchlight
Local 24-hour Distress Line: 519-821-3760
Toll Free 24-hour Distress Line: 1-877-821-3760
Local 24-hour Crisis Line: 519-821-0140
Toll Free 24-hour Crisis Line: 1-877-822-0140
Website: http://www.communitytorchlight.com/

Family Counselling and Support Services for Guelph-Wellington
Website: http://www.familyserviceguelph.on.ca
Phone: 519-824-2431

For Everyone:

Canadian Cancer Society
Website: http://www.cancer.ca/en/?region=on
Online community: cancerconnection.ca
Information line: 1-888-939-3333

TeleHealth Ontario
Telephone: 1-866-797-0000

IF YOU FEEL LIKE HARMING YOURSELF OR OTHERS, CALL 911 IMMEDIATELY.
Subject: Recruitment for study of the experience of parental cancer

Hello _______

Thank you for your interest in participating in my study of the experiences of parental cancer. My name is Christine McPhail. I would like to ask you a few questions to determine whether you should participate in this study or not.

Are you 18-29 years of age?

Are you a university or post-secondary student?

Has your parent had cancer while you were between the ages of 18 and 29?

Do you consider yourself to be fluent in English?

Are you comfortable participating in a private interview (1-1.5 hours in length) about your experience with parental cancer?

I am going to send you a letter of informed consent on this study. It will describe the study in detail so that you can make an informed choice as to whether to participate or not. Then, if you want to participate, you can contact me again to set up a date and a time for the interview.

Thanks so much for your interest. If you have any questions, please don’t hesitate to ask.

Sincerely,

Christine McPhail, BASc.
MSc. AHN student
Department of Family Relations and Applied Nutrition
University of Guelph
Guelph, ON, N1G 2W1
The members of the University of Guelph Research Ethics Board have examined the protocol which describes the participation of the human subjects in the above-named research project and considers the procedures, as described by the applicant, to conform to the University’s ethical standards and the Tri-Council Policy Statement, 2nd Edition.

The REB requires that you adhere to the protocol as last reviewed and approved by the REB. The REB must approve any modifications before they can be implemented. If you wish to modify your research project, please complete the Change Request Form. If there is a change in your source of funding, or a previously unfunded project receives funding, you must report this as a change to the protocol.

Unexpected events and incidental findings must be reported to the REB as soon as possible with an indication of how these events affect, in the view of the Responsible Faculty, the safety of the participants, and the continuation of the protocol. If research participants are in the care of a health facility, at a school, or other institution or community organization, it is the responsibility of the Principal Investigator to ensure that the ethical guidelines and approvals of those facilities or institutions are obtained and filed with the REB prior to the initiation of any research protocols.

The Tri-council Policy Statement, 2nd Edition, requires that ongoing research be monitored by, at a minimum, a final report and, if the approval period is longer than one year, annual reports. Continued approval is contingent on timely submission of reports.

Membership of the Research Ethics Board - General: S. Banerjee, Community Member; J. Carson, Community Member; S. Chuang, FRAN (alt); K. Chuong, Graduate Student; J. Clark, PoliSci (alt); J. Dwyer, FRAN; M. Dwyer, Legal; B. Ferguson, CME (alt); B. Giguerie, Psychology (alt); B. Gottlieb, Psychology; S. Henson, OAC (alt); S. Hickson, COA; L. Kuczynski, Chair; A. Lauzon, OAC, R. Ragan, Legal (alt); C. Rice, FRAN; V. Shalla, SOAN (alt); R. Stansfield, SOAN; J. Wood, Graduate Student (alt); S. Yi, CME.

Approved:
per
Chair, Research Ethics Board – General
CONSENT TO PARTICIPATE IN RESEARCH

“The experience of parental cancer in young adult post-secondary students and its influence on health beliefs and attitudes”

You are asked to participate in a research study conducted by Christine McPhail (MSc Student), John Dwyer (PhD), Michèlé Preyde (PhD), and Rebecca Hanemaayer (Undergraduate Thesis Student) from the Department of Family Relations and Applied Nutrition at the University of Guelph. This study and the interviews involved will be carried out by Christine McPhail in partial completion of a Master of Science degree.

If you have any questions or concerns about the research, please feel free to contact:

<table>
<thead>
<tr>
<th>Christine McPhail</th>
<th>John Dwyer</th>
</tr>
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<tbody>
<tr>
<td>Phone: 519-731-2167</td>
<td>Phone: 519-824-4120, ext. 52210</td>
</tr>
<tr>
<td>Email: <a href="mailto:cmcphail@uoguelph.ca">cmcphail@uoguelph.ca</a></td>
<td>Fax: 519-766-0691</td>
</tr>
<tr>
<td></td>
<td>Email: <a href="mailto:dwyer@uoguelph.ca">dwyer@uoguelph.ca</a></td>
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**PURPOSE OF THE STUDY**

The purpose of this study is to examine and explore the experience of parental cancer by young-adult post-secondary students and how the experience influences health beliefs and attitudes.

**PROCEDURES**

If you volunteer to participate in this study, we will ask you to do the following things:

1. Arrange a meeting time with the researcher, Christine McPhail (interviews will take place at the University of Guelph, City of Guelph Campus)
2. Complete a consent form and provide some information about your age, gender, where you were born, ethnic background, and past education before your interview (this will only take a few minutes).
3. Participate in an in-depth semi-structured interview with the student researcher, Christine McPhail (this will take approximately 60-90 minutes).
4. If you choose to, review and comment on the themes and illustrative quotes identified by the student researcher, Christine McPhail, at a later date once all interview transcripts have been analyzed.

To make sure the researcher keeps an accurate account of the interview results, interviews will be recorded on a portable audiotape recorder and will be typed up at a later time for analysis.

**POTENTIAL RISKS AND DISCOMFORTS**

Due to the personal nature of the interview questions, some participants may become upset or emotionally distressed during or following the interview. As such, a variety of distress and crisis resources will be provided to you before beginning the interview. If you become emotionally upset during the interview, the interviewer will pause, allow you to take a break from the interview and/or call a distress line in privacy, and the interviewer will provide you with the opportunity to withdraw from the interview immediately. You are encouraged to use the distress/crisis
resources if you feel the slightest bit uncomfortable. Furthermore, while only participants who feel comfortable participating in a 60-90 minute interview are encouraged to participate, the interview will be terminated at any point if you feel too uncomfortable to continue.

POTENTIAL BENEFITS TO PARTICIPANTS AND/OR TO SOCIETY

You will get the chance to share your personal experience with parental cancer in a safe space.

On a larger scale, the results of this study will help to better understand the experience of parental cancer in young adult post-secondary students and could possibly be considered by researchers and practitioners in the care of family and offspring when a parent has cancer.

PAYMENT FOR PARTICIPATION

You will receive a token of appreciation of $20 for participating in this research. You will receive it if you decide to withdraw from the study. You will be required to initial a form confirming that you have received $20 from the interviewer.

CONFIDENTIALITY

Every effort will be made to ensure confidentiality of any identifying information that is obtained in connection with this study.

To ensure confidentiality, no identifying personal information needed for this study will be available to anyone other than the four researchers identified at the beginning of this form. Contact information will be required for the purpose of setting up a meeting time and so that you can be sent a summary of overall research findings and/or an outline of identified themes and quotes for review. However, this information will not be directly attached to recorded interviews or interview transcripts; only unidentifiable ID codes or pseudonyms will be used. Furthermore, names, organizations, work titles, and any other identifying information will be altered in the interview transcripts to ensure confidentiality. Audiotapes of the recorded interviews will be kept in a secured and locked cabinet in the Department of Family Relations and Applied Nutrition at the University of Guelph. Audiotapes that have been typed up will be encrypted (this means that the words in the document are rearranged, which makes the document unreadable without proper resources) and secured on a hard-drive, accessible only by the researchers. At no time will the identities of participants be available to others. Interview data on audiotapes and the hard-drive will be kept for 5 years after the publication of this research and then they will be destroyed.

PARTICIPATION AND WITHDRAWAL

You can choose whether to be in this study or not. If you volunteer to be in this study, you may withdraw without consequences of any kind. You may exercise the option of removing your data from the study. You may also refuse to answer any questions you don’t want to answer and still remain in the study. The researcher may withdraw you from this research if circumstances arise that warrant doing so.

*NOTE: If you complete the interview, you may withdraw from the study up until one week following the interview and then your recorded interview will be permanently destroyed.

RIGHTS OF RESEARCH PARTICIPANTS

You may withdraw your consent at any time and discontinue participation without penalty. You are not waiving any legal claims, rights or remedies because of your participation in this research study. This study has been reviewed and received ethics clearance through the University of Guelph Research Ethics Board. If you have questions regarding your rights as a research participant, contact:

Sandy Auld, Director, Research Ethics
Telephone: (519) 824-4120, ext. 56606
SIGNATURE OF RESEARCH PARTICIPANT

I have read the information provided for the study “The experience of parental cancer in young adult post-secondary students and its influence on health beliefs and attitudes” as described herein. My questions have been answered to my satisfaction, and I agree to participate in this study. I have been given a copy of this form.

______________________________
Name of Participant (please print)

______________________________     ____________
Signature of Participant                  Date

SIGNATURE OF WITNESS

______________________________
Name of Witness (please print)

______________________________     ____________
Signature of Witness                  Date
7.8 Appendix H: Form Indicating Desire to Receive Summary of Study Results

REQUEST TO RECEIVE A SUMMARY OF RESEARCH FINDINGS AND/OR PROVIDE FEEDBACK ON THE THEMES AND QUOTES IDENTIFIED IN THE ANALYSIS

Would you like to receive a summary of the results of this overall research project?
___ Yes
___ No

Would you like to review the themes and quotes identified and share your opinions on what you think of them?
___ Yes
___ No

If you indicated “Yes” to either of the above questions, please indicate whether you would prefer to be contacted by email or mail and write your contact information below (You do not need to include your name).

___ Email
___ Mail

Email or Mailing Address:
____________________________________________________________________________
____________________________________________________________________________
____________________________________________________________________________

Participant #___
Initials: ___________________________
7.9 Appendix I: Proof of Participant Compensation

Please initial this section to confirm that you have received $20 as appreciation for participating in this study.

Participant #____
My initials on this page indicate that I have received $20 in cash for participating in the study “The experience of parental cancer in young adult post-secondary students and its influence on health beliefs and attitudes” by Christine McPhail

Initials ______________________

Thank you very much for your participation!
7.10 Appendix J: Remaining Themes

This appendix section provides themes that were not included in the manuscript because they did not have enough richness, they were not relevant to the research objectives, or only one participant discussed the theme. Themes and sample quotes for various topics discussed are presented.

Causes of cancer:

- Longer lifespan as a possible cause for cancer.
  
  I think we have longer lifespans . . . people aren't dying at 30 anymore, so by the time you reach 40 or 50, you've got all these new things coming out of nowhere and hitting you. (Participant #12)

- Physical characteristics that put someone at risk for developing cancer.
  
  I guess there's a lot of things now that can cause it, but from his specific situation, it would I guess be skin damage from the sun. He's very pale so he's prone to getting it, I guess. (Participant #3)

- Treatment occurring too late in the disease progression as a possible cause for reoccurring cancer or the severity of current cancer.
  
  He had this very strange cough for the longest time and we didn't know what it was, and it turned out that it was due to his low blood cells so he was having a hard time breathing. So I think what happened was just because he didn't look after it for so long. He just kind of put it all inside and didn’t get checked out. It kind of rapidly got worse. Fortunately it was able to be cured but I think the leading contributor to why it got so out of control was because he didn't really address it. (Participant #16)
So technically the breast cancer is what caused the initial cancer, but honestly, she had a lot more issues because of just wrong diagnosis in the hospital. I was really pissed off because she would undergo surgery after surgery to try and get rid of whatever was in her leg right, and in my opinion, they just didn't know what it was and it pissed me off that they couldn't tell me what it was . . . and because of the surgeries it just got worse and it got aggravated and then bacteria got into it.” (Participant #15)

**Prevention of cancer:**

- Medical procedures that can be used to prevent cancer.
  
  I've heard of people getting I think it's mastectomies and that's to decrease the risk of breast cancer. I feel like I’ve heard it does tend to help. (Participant #7)

- Alternative remedies (health care and other).
  
  I don’t know if being a positive person helps . . . I really subscribe to that. I know it can help for sure in the healing process and laughter is the best medicine obviously but I don't know if someone from a medical standpoint would say that. They'd say no that there's no real evidence to support that and I’m not sure if there is. (Participant #12)

Drinking lots of hot lemon water I heard that reduces tumor size and I've heard about reducing the risk . . . eating healthy food and green tea. (Participant #13)

**Concern:**

- Cancer affecting your life. Cancer can affect your life in a negative way and that is why it’s concerning.
  
  Because it's just . . . anything that kind of takes over your body and goes against it. It just has such power over you, to affect how you feel and how long you live . . . when we first
found out . . . my idea of cancer was “oh my gosh, this is the worst thing in the world and it's irreversible” . . . and he couldn't have surgery either. It was too far past so if you can't operate and you can't fix it, you know, the way the doctors say, then what are you going to do? I think of it as more fluid now. (Participant #13)

**Source of knowledge:**

These themes came about when participants discussed where they had learned about cancer. These themes were excluded from the results and manuscript because they didn’t address any of the objectives. However, the data could be useful in the future.

- Knowledge of cancer from school.
  
  Nutrition. I learned about it first in health sciences. We did a lot of stuff in first year, which was a while ago now. We did stuff on cancer in that year and just through university. I don't know how much information I got from when my mom was going through it. I think more of it was from school, even probably starting in high school and then it continued. (Participant #11)

- Learning from experience with cancer.
  
  I guess just from people I know who have cancer or who have had cancer . . . I guess . . . the main two people that I have learned about or learned that through are my grandfather, not on my dad’s side, and my dad. My grandpa was an alcoholic and he smoked a lot and he died of lung cancer and liver cancer and I think I connected his alcoholism with damage to the liver, so that was the main cause and effect. You drink a lot, then your liver is going to be shot. (Participant #13)

- Confusion about what causes cancer.
  
  I'm sure it's coming from kind of the same place. Oh no, actually thinking back now, I
don't know much about how it starts. You know about it when it happens. (Participant #15)

- Media and society as the source of knowledge.

  I guess probably education and the media. (Participant #4)

**Parent’s beliefs about their cancer:**

Participants were asked to comment on what they knew about their parent’s beliefs about the cause of his or her cancer. This was a topic that came up because of the discussion that I was having with participants about their experience with parental cancer, but it was not relevant to the research objectives. The following themes came out of this conversation.

- Genetics and physical characteristics playing a role in the development of the parent’s cancer.

  I think he was under the impression that it's genetic as well. Like I said, my uncle got it and it was just like he was next in line or something like that. (Participant #12)

- Many participants did not have a discussion with their parent about the possible causes of that parent’s cancer.

  We didn't really talk about it that much . . . he let us know what was going on and he made it clear that we could discuss it. But while I was away from home and he was undergoing the main treatment, . . . we wouldn't have in-depth discussions. (Participant #12)

- Parents sometimes believed that if they had lived a healthier lifestyle, they would have reduced their chances of getting cancer.

  After his diagnosis, he started taking a lot more supplements, so I believe he thinks there’s more of a very direct biological link between something and his cancer versus it
just being genetic-based and overall wear and tear. I think he does somehow think that he should have been healthier throughout his life and maybe he could've avoided this.

( Participant #1 )

**Changes parents made and other outcomes of being diagnosed with cancer:**

- Participants discussed their parent altering life priorities.

  I feel like his whole view on life changed. Being that close and just realizing everything that he had going. I feel like he was neglecting that for so long and now I feel like he's taking more time to talk to me and talk to my brothers and to do things he loves.

  (Participant #16)

- Participants discussed how their parent became more grateful.

  She is very grateful for what she had. That is what she always used to tell me . . . don't take everything for granted. Be grateful for everything you have because everyday when you're healthy is a blessing. (Participant #6)

- Participants’ parent had also discussed relationship changes.

  My aunt (her sister) is a lot closer now. They come over all the time and she was three hours away so she went over a lot in the summer and friends obviously came over and talked to her more as well. (Participant #14)

- Participants discussed how their parent lost his/her feelings of invincibility.

  He saw himself as no longer invincible and he actually saw himself getting older . . . They have to take advantage of things now. (Participant #1)

- Participants also saw their parent begin to prioritize his or her health.

  The diagnosis was a huge push so that's what made him decide. So that was a big change
and I think just his whole mentality was like “Okay, I'm going to change everything and just focus on health.” (Participant #13)

- Participants saw their parent make health behaviour changes that included managing stress, eating a healthier diet, and being more active.

She got back into shape. She was overweight after having her third child and it's easier just to cook us all chicken nuggets and everything . . . She went on a huge health bender. (Participant #17)

- Participants saw that there were barriers their parent faces to making lifestyle changes.

The major barrier that participants discussed was the issue of lifelong habits.

I think that it's just hard for her because . . . I'll go back to the food issue. It’s hard for her because she came from a fairly abusive household where food was a very big comfort for her and if food is a comfort for you for so many years, it's just really hard to break . . . it's not as easy for her to lose weight like that but it's a habit that she's trying to break. (Participant #8)

- Lessening workload.

She doesn't work. She's at home right now currently. She went on a leave of absence . . . it's kind of been like non-stop since I was around 17, that's when it got really bad . . . so she hasn’t been back to work since then. (Participant #15)

**Outcomes of having a parent with cancer:**

- One participant discussed the idea of her experience building her faith.

My family is religious. We're of a Christian background so I guess it's building our faith more. . . . We don't have anything else to go on right now so it's just trusting that he'll be healed I guess . . . there's no treatment and the doctors can't do anything. (Participant #3)
Two participants discussed how their experience with parental cancer has left them feeling financially burdened.

I was stressing out about everything, and then ever since I’ve had a job, it's just typical university tuition you have to work a lot to pay for it. So that brought it down. I didn't get as involved second semester either just because I didn't have the time. That was one big thing. (Participant #10)

Participants found that it increased awareness of cancer in society.

Before, cancer was “Oh, we do a terry fox walk every year with the school and you walk around the block.” Now, it's like okay, you're raising money actually for something and you can make a connection with it. . . . it opened my eyes to not the bad part of life but the more real part of life. (Participant #2)

Some participants found their experience to give them motivation for a cause.

I've never been more motivated for a cause before. . . . I've always wanted to be in a helping profession but I'm now a regular volunteer at the Canadian Cancer Society and Children's Wish Foundation and stuff like that. I just believe in something so much now because I hate it so much. (Participant #5)

Some participants talked about being more sensitive when discussing cancer.

I definitely get more sensitive with people. If I don't like when someone says something to me, I'm more likely to speak my mind than I used to because I just don't have as much patience as I used to. (Participant #9)

Some participants stated that they did not experience any changes in their social life.

I don't think I lost or gained any friendships because of it. (Participant #4)
Coping:

- Some participants discussed using positive health changes to cope.
  
  I go for runs and exercise when I'm feeling stressed out, so that works. (Participant #3)

- One participant discussed writing thoughts down as a way of coping.
  
  I write things down so my mind won't be too overwhelming. Sometimes I feel like it's going to explode with all the thoughts that I keep to myself. So right now, I write things down and I try to open up myself more. (Participant #6)

Support systems:

- Participants discussed how their family received meal support.
  
  Just like friends and family bringing some food over sometimes. Especially when my mom had surgery. (Participant #11)

- Some participants received financial support.
  
  We have a lot of financial support on certain aspects from the Canadian Cancer Society, like paying for flights when my parents had to go back and forth to Toronto before the transplant. They helped out with a lot of their flights a lot. (Participant #9)

- Some participants talked about receiving support from the healthcare system and staff.
  
  I think it's just my doctors have really been helpful because they know about it, so they can kind of put me in the right direction and they're open to answer questions. (Participant #8)

- A participant discussed her family’s spiritual support.
  
  I think it definitely has . . . the support from our church has been effective. There has been so many people who have been caring. (Participant #3)
Influence of life at university:

- For two participants, the experience of parental cancer affected their choice of studies. I think it affected me in a positive way for sure. I’m even looking into doing... I want to go into nutrition. Now I’m getting my commerce degree and then I want to do a fifth year at a different school for holistic nutrition. So that's kind of cool and I would not have even, well I don’t know but if my dad didn’t get diagnosed, then [I would not have even] have opened my eyes to how important what you put in your body is and how you treat your body. (Participant #10)

Motivator for making positive lifestyle changes:

- A few participants discussed how positive role models in their life helped motivate them to make positive health changes.

  I've really found a new hobby for me and it's opening up a lot of new friendships with people I kind of like. I find people who take care of themselves physically have really good self-esteem. (Participant #2)