

Bridging the Gap – A Grounded Theory of Cancer Coaching Experiences

By

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ABSTRACT

Cancer incidence is increasing and so are survival rates. The aftermath of cancer includes multi-dimensional and long-lasting effects that prevent individuals from recovering and re-integrating into their daily routines. Cancer systems attend to patients during diagnosis and treatment, but often fall short in providing continuity of care afterward. This results in a considerable number of individuals living with the effects of cancer, with little support care. While there are evidence-based recommendations to improve follow-up cancer care, the extent to which they have been implemented remains unknown. To support the needs of cancer survivors The Ottawa Regional Cancer Foundation developed a Cancer Coaching Program (CCP). As life and health coaching interventions have been shown to benefit this population, this study aimed to explore the impacts of the CCP on the lives of cancer survivors. Using a grounded theory approach, the experiences of (n=12) cancer survivors who had previously participated in the program were explored, to create an explanatory model. Descriptive results depicted various beneficial outcomes to participating in the CCP. The dominant role of the CCP is to support survivors by “bridging the gap” to survivorship, through tailored coaching services. This study provides insight into the mechanisms that work for this cancer coaching program, which may be helpful for other programs exploring strategies to assist this population.

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CHAPTER 1: Introduction

1.1 Background

Cancer survival rates have significantly improved in Canada, with the five-year relative survival rate having increased by 7.3% between 1992 to 1994, and 2006 to 2008 (Canadian Cancer Society, 2014). According to 2006-2008 estimates, Canadians have a 63% chance of surviving at least five years after their diagnosis (Canadian Cancer Society, 2014). This is in part due to research developments, improvement of medical treatments, and early detection (Stanton, 2012). Combined with an aging population and increasing cancer incidence, the number of people with “the experience of living with, through and beyond a diagnosis of cancer” (Jefford, Karahalios, Pollard, Baravelli, Carey, Franklin, Aranda, & Schofield, 2008, p. 20) is continuously growing and is expected to triple to 75 million people worldwide in 2030 (Boyes, Girgis, D’Este, & Zucca, 2012). This results in a vast population living with the traumatic effects of cancer (Love & Sabiston, 2011).

Many survivors of cancer report long-term psychological, physical, practical and emotional consequences that are related to the disease and its treatments (Campbell, Sanson-Fisher, Turner, Hayward, Wang, & Taylor-Brown, 2011; Jefford et al., 2008). Among the various challenges patients and their families encounter in the survivorship stage of cancer - psychosocial care remains one of the most prevalent areas of unmet needs (Jefford et al., 2008; Campbell, et al., 2011; Molassiotis, Wilson, Blair, Howe & Cavet, 2011; Liao, 2011; Annunziata, Muzzati & Bidolli, 2011; Chambers, 2011; Jacobsen & Wagner, 2012; Boyes et al., 2012; Simard, Thewes, Humphris, Dixon, Hayden, Mireskandari, & Ozakinci, 2013; Sperling, Sandager, Jensen & Knudsen, 2014; Schulte, 2014).

The term ‘psychosocial’ is widely used in the literature, however as Martikainen, Bartley and Lahelma (2002) have determined, its roots remain tied to the World Health Organization definition of health as: “a state of complete physical, mental and social well-being, and not merely the absence of disease and infirmity” (p.1091). While this definition of health has been criticized over the decades, it highlights the importance of considering psychosocial factors in a person’s overall health, which is of importance for a person who has experienced difficulties caused by an illness such as cancer. For the purpose of this thesis, psychosocial health needs are presented as the practical, emotional/psychological and interpersonal aspects necessary for cancer survivors to attain an optimal well-being. Psychosocial care is a crucial element in the cancer continuum, which includes the stage beyond treatment (Schulte, 2014). Follow-up care and survivorship programs should therefore prioritize psychosocial support, as complete and healthy rehabilitation depends on it. (Schulte, 2014; Canadian Cancer Society Steering Committee, 2009).

1.2 Cancer Survivor

The survivorship stage of cancer has been “largely neglected in clinical practice, education and research” and has been considered as a distinct phase in the cancer continuum only in the recent decade (Howell et al., 2012, p.360). For this reason, the term “survivor” is widely used and there remains a general lack of consensus on how it should be defined (Cheung & Delfabbro, 2016). Many adopt the traditional definition that one is considered to be a cancer survivor only after being cancer free for five years (Jefford et al., 2008; Canadian Cancer Society, 2014; Cheung & Delfabbro, 2016). Others, based on conversations with the participants of this study as well as members of the Ottawa Regional Cancer Foundation, consider being a “survivor” from the moment they are diagnosed with cancer. The National Coalition of Cancer Survivorship defines a

cancer survivor as someone who has experienced “living with, through and beyond a diagnosis of cancer” (Jefford et al., 2008, p.20) and includes family members, friends and caregivers as they too, are impacted by the survivorship experience (National Coalition for Cancer Survivorship, 2012). Alternatively, Cheung and Delfabbro (2016) reveal that identification with the term “cancer survivor” depends not on receiving a cancer diagnosis or completing treatments, but when an individual personally decides that the battle is over. While the author of this present study acknowledges all various definitions of the term “cancer survivor” as well as personal preferences for using them, specific criteria for recruitment were established for the feasibility of the research. In this study we consider cancer survivors as having received a diagnosis, completed curative treatments and surgery, and prior to development of a recurrent cancer.

1.3 Cancer Coaching Program

Each hour, approximately 22 people in Canada are diagnosed with cancer (Canadian Cancer Society, 2014) and during their journey, it is estimated that they will come in contact with eight medical professionals for no longer than 15-minute sessions (Ottawa Regional Cancer Foundation, 2014c). This statistic depicts a cancer system that is difficult to navigate. For most, limited contact with cancer professionals is not enough to help them come to terms with their new reality; and to understand, to feel in control of, and to determine their next steps (Ottawa Regional Cancer Foundation, 2014c). To address this discrepancy, the Ottawa Regional Cancer Foundation (ORCF) developed the Cancer Coaching Program - currently at the Maplesoft Centre in Ottawa, Ontario - that helps individuals in all stages of cancer, as well as their families, cope with the emotional, physical and practical effects of cancer (Ottawa Regional Cancer Foundation, 2013a). This program adopted a person-centered approach that allows clients to orient cancer care toward their personal goals and to find solutions that work best for them. By allowing clients

to lead, they develop the autonomy and courage necessary to manage their personal lives and their health care. This program was designed under the assumption that tailoring support to each individual client ensures needs are met and outcomes are positive and sustainable.

Cancer coaching is delivered via cancer coaches, who are trained professionals from diverse backgrounds - such as social work, nursing and occupational therapy - with expertise in oncology (Ottawa Regional Cancer Foundation, 2015b). Their goals are to support, empower and connect with patients and their families to help them understand the diagnosis and treatment options, prepare for their next medical appointments, and manage side effects and lifestyle changes (Ottawa Regional Cancer Foundation, 2014a). Cancer coaches help clients organize a health and social team and connect them to the resources available in the community (Ottawa Regional Cancer Foundation, 2014a). Additionally, they facilitate a smooth transition back to work, provide emotional and spiritual support to help cope with fear and sorrow, help find strategies to overcome and manage obstacles, and provide support for caregivers (Ottawa Regional Cancer Foundation, 2014a).

Due to generous donations made to the ORCF, clients can receive up to five hours of coaching free of charge without referral requirements (Ottawa Regional Cancer Foundation, 2015a). Entry into the coaching program includes an optional, but recommended client information session, online or paper registration, and then clients are triaged and matched with a coach. All coaches are trained with the same coaching model but client-coach matching is based on client needs, and coaches' backgrounds, knowledge and experience, as well as availability.

1.3 Research Questions & Objectives

The purpose of this study was to explore the lived experiences and psychosocial impacts of participation in a Cancer Coaching Program (CCP) implemented by the Ottawa Regional Cancer Foundation (ORCF) and to develop a grounded theory explaining the support provided by the coaching process.

The specific research questions and corresponding objectives are:

(1) What types of issues are encountered by cancer survivors seeking support from the CCP?

Objective: Use patient narratives to outline prevalent issues encountered by cancer survivors who were enrolled in the CCP.

(2) How is the CCP helpful for cancer survivors?

Objective: Use detailed interviews to identify and describe the program's most valuable attributes.

(3) How does the CCP experience vary across different demographics?

Objective: To outline differences and similarities in experiences across diverse demographic factors.

CHAPTER 2: LITERATURE REVIEW

A review of literature is presented in this chapter and is categorized into three main themes: 1) Psychosocial Challenges Around Cancer Survivorship; 2) Survivorship and Follow-up Care; and 3) Coaching Interventions. These categories represent predominant themes in the literature for cancer survivors and their families, as well as for health coaching.

Online databases such as Scopus, Cumulative Index to Nursing and Allied Health Literature (CINAHL), as well as the Internet search engine Google Scholar, were used to retrieve relevant literature. Keywords such as: Cancer survivors, cancer survival, cancer in Canada, cancer survivorship, post-cancer care, survivorship care, supportive care needs, cancer survivor needs, psychological support for cancer survivors, psychological impact of cancer, life after cancer, post-treatment care, were used as search terms. Articles related to paediatric cancer and childhood survivors of cancers were excluded from the search. Coaching is a relatively new intervention strategy, therefore there is minimal literature discussing this type of intervention. As a result, articles on life coaching, personal coaching, health coaching and physical activity counseling were reviewed to provide an overview of this type of personalized support.

2.1. Psychosocial Challenges Around Cancer Survivorship

Receiving a cancer diagnosis is a frightening experience as it “[...] marks an immediate passage from a condition of health to one characterized by uncertainty, threat of death, role, and physical changes” (Annunziante & Muzzatti, 2011, p.291). Indeed, the experience of cancer and its intensive treatments can be quite strenuous as it takes a severe toll on the body, physically and mentally, and continuously so even after treatments are completed (Jefford et al., 2008). Many survivors endure life-long psychological, social, emotional, physical and spiritual effects as a result of the cancer itself and its treatments (Jefford, Rowland, Grunfeld, Richards, Mahers &

Glaser, 2012; Jefford et al., 2008). While every cancer experience is unique, the survivorship literature supports Rowland's (1990) assumption "[...] that regardless the type of cancer, all people diagnosed with cancer experience altered relationships, dependence–independence issues, achievement disruptions, impact on body and sexual image and integrity, and existential issues" (Zebrack, Yi, Petersen, & Ganz, 2008, p.891). Psychosocial implications Chesler and Barbarin's (1987) key domains of stress, practical, emotional/psychological and interpersonal issues will be presented in this section, to discuss their implications for cancer survivors.

2.1.1 Practical Issues

After enduring several procedures and treatments, cancer survivors often experience treatment-related impairments and impacts on daily life routines and work (Mehnert & Koch, 2013; Zebrack & Isaacson, 2012). Adverse treatment effects often result in a range of practical challenges such as loss of income, limitations on work performance, change in roles and physical limitations (Jefford et al., 2012). For instance, fatigue is reported among many cancer survivors as a significant barrier to returning to their normal routines (Jefford et al., 2008).

While 63.9% of cancer survivors return to work, many encounter problems as they re-integrate into the workplace (Mehnert, de Boer & Feuerstein, 2013). Many cancer survivors report that they have encountered negative assumptions regarding their abilities to perform job responsibilities, dismissal, demotion, denial of promotion, undesirable transfer, denial of benefits and hostility (Hewitt, Greenfield & Stovall, 2006). A history of cancer significantly impacts employment opportunities and the attainment of health and life insurance, as adults of childhood cancer report being unemployed because of health-related issues six times more than healthy siblings, and are almost twice as likely to be seeking work but remain unemployed (Kirchhoff, Leisenring, Krull, Ness, Friedman, Armstrong, Stovall, Park, Oeffinger, Hudson, Robinson & Wickizer, 2010; Hewitt, Greenfield & Stovall, 2006).

While Canada has laws such as the Employment Equity Act and Ontarians with Disabilities Act, survivors of cancer face substantial employment obstacles (Hewitt, Greenfield & Stovall, 2006; Government of Canada, 2009). Cancer poses an important financial burden due to time away from work, medical and related costs (such as medications, nutritional supplements, appointments with various health professionals, transportation, homecare etc.) as well as existential costs (such as household situations) (Sharp, Carsin & Timmons, 2013). Cancer-related financial stress is “[...] consistently associated with increased risk of adverse psychological outcomes and particularly strongly with severe depression, anxiety or distress” (Sharp, Carsin & Timmons, 2013, p.754). Not only are career opportunities and financial status and earnings threatened by a history of cancer and its treatments, but disruptions to daily hobbies, family dynamics and social involvement represent common practical issues experienced in the survivorship stage, which influences a myriad of emotional issues in cancer survivors (Jefford et al., 2008; Muriel, Moore, Baer, Park, Kornblith, Pirl, Prigerson, Ing, & Rauch, 2012).

2.1.2 Emotional / Psychological Issues

When life is disrupted by an illness such as cancer, a range of emotional needs is inevitable (Zebrack & Isaacson, 2012). Many survivors of cancer experience psychological effects; 30% live with depression or anxiety (Sharp, Carsin & Timmons, 2013). The most frequently reported psychological impact is fear of recurrence, which includes feelings of uncertainty and death (Hewitt, Greenfield & Stovall, 2006; Jefford et al., 2008; Jefford et al., 2012; Simard et al., 2013; Ghazali, Cadwallader, Lowe, Humphris, Ozakinci, & Rogers, 2013; Koch, Jansen, Brenner & Arndt, 2013). This fear, as well as anxiety related to the unknown, is closely linked to apprehension about leaving the security of the health care system and the periodic care of a health professional (Jefford et al., 2008; Jefford et al., 2012). Fear of recurrence is prevalent in 33% to 96% of cancer survivors and can significantly impact their daily routine, even causing

psychosocial morbidity (Ghazali et al., 2013). Moreover, survivors face various changes in their physical appearances including weight change, amputations and physical/sexual dysfunction that have important psychological demands such as, rediscovering self-esteem and identity, as well as developing a healthy body image (Zebrack & Isaacson, 2012; Roland, Rodriguez, Patterson & Trivers, 2013).

There is a strong association between the risk of psychological distress for cancer survivors and their level of physical disability, more so than at the stage of diagnosis or treatment (Bank, Byles, Gibson, Rodgers, Latz, Robinson, Williamson, & Jorm, 2010). In a study by Jefford et al. (2008), the most common descriptions after one year of completing treatments were feeling low, depressed, down, emotional, isolated and vulnerable. While completing treatments and being declared free of cancer is what most hope for, many do not experience the sense of relief they and their families were expecting (Jefford et al., 2008). Thus, the survivorship stage of cancer encompasses a significant emotional and psychological strain on the individual, which is often unexpected.

2.1.3 Interpersonal issues

Relationships are profoundly affected by a cancer diagnosis as some survivors describe others not knowing what to say to them or how to behave with them, and they themselves having difficulties relating to others; this is in part due to a change in outlook, priorities and attitude towards life as a consequence of having experienced cancer (Jefford et al., 2012). In fact, one study showed interpersonal tension as being a common stressor in a survivor's daily life (Constanzo, Stawski, Ryff, Coe, & Almeida, 2012). As more patients are surviving cancer, and the psychosocial impacts are known to be long-term, it is important to consider the impact on family dynamics, such as marital and parental relationships (Stanton, 2012; Jefford et al., 2008; Schmitt, Piha, Helenius, Baldus, Kienbacher, Steck, Thastum, Watson & Romer, 2008).

Approximately 22.4% of new cancers occur in individuals between 21 and 55 years old; which for many is during the phase of life where being a parent is a primary role. It is estimated that 14% of American cancer survivors live with minor children (Muriel et al., 2012; Weaver, Rowland, Alfano, & McNeel, 2010). As survivors enter survivorship, the family often anticipates the return to 'normal', however many psychological and physical impacts, such as fatigue, persist for a long period of time. This can be difficult for family members to comprehend, given the completion of treatments. One study participant described her children questioning the legitimacy of her fatigue "[...] when her daughter came home from school one day and saw her in a nightgown, she said, [...] 'Can't you get over this? Why are you still in bed?' [...] 'They hate it. They hate that I nap. It reminds them that I was sick, and I'm still not better yet, and frankly, I think they think I'm lazy.'" (Oktay et al., 2011, p.131). The inability to perform usual familial roles can negatively impact parent-children relationships and many survivors choose not to reveal their issues to their children in hopes to keep their lives as normal and unaffected as possible (Oktay, Bellin, Scarvalone, Appling, & Helzlsouer, 2011).

The long-term effects of cancer also pose a stress on the spouse who often must fulfil dual parental roles (Oktay et al., 2011). Post-treatment effects can impact emotional and sexual relationships, especially when cancer treatments contribute to low self esteem, alteration of the body, and infertility, such as for prostate, testicular, breast and ovarian cancers (Zebrack & Isaacson, 2012; Carpentier & Fortenberry, 2010). Relationships also suffer when post-treatment effects prevent a couple from sharing time together and doing the activities that were at the basis of their relationships pre-cancer (Oktay et al., 2011)

Psychological distress in adult cancer survivors is prevalent and symptoms can last up to 10 years following cancer treatments (Sharp, Carsin & Timmons, 2013; Ghazzali et al., 2013; Harrington, Hansen, Moskowitz, Todd, & Feuerstein, 2010). Although gaps in the psychosocial health

services for cancer survivors have been identified, patients frequently report that psychological and support needs are not being adequately met (Jefford et al., 2013; Schulte, 2014). Guidelines and standards of care are available, but to date have had limited impact on psychosocial service delivery in clinical practice (Jacobsen & Wagner, 2012). Improvements in psychosocial care are more likely to occur if service quality is actively monitored and if providers and other interested parties are provided with the results (Jacobsen & Wagner, 2012). The Canadian Partnership Against Cancer and the Canadian Association of Psychosocial Oncology have established clear and evidence-based recommendations for psychosocial care for cancer survivors (Howell, Hack, Oliver, Chulak, Mayo, Aubin, Chasen, Earle, Friedman, Green, Jones, Jones, Parkinson, Payeur, Sabiston, Sinclair, & Tompson, 2011) however the extent to which they have been implemented and the direct psychosocial impact on survivors is unknown.

2.2 Follow-up Cancer Care

The focus of cancer care is often on diagnosis and treatment, and less toward post-treatment rehabilitation (Jefford et al., 2012). As the aged population is booming, cancer incidence is rising and survival rates are improving, there is an urgent need to address needs of cancer survivors and the issues they face (Jefford et al., 2008; Stanton, 2012; Boyes et al., 2012; Canadian Cancer Society, 2014).

Consequently, it has included “the domains of psychosocial and supportive care, health promotion, surveillance and long-term monitoring and early detection for late and long-term effects” (Howell et al., p.360). While it is part of the national agenda, the development of a sustainable model of follow-up care provision for cancer survivors is still in its infancy phase (Howell et al., 2012; Sussman, Souter, Grunfeld, Howell, Gage, Keller-Olaman & Brouwers, 2012; Howell et al., 2011; Canadian Partnership Against Cancer, 2012).

2.2.1 Follow-up Care

It has been reported that 71% of survivors will develop at least one serious health problem such as cardiomyopathy, neuropathy, mood disturbance, cognitive disorders, bone loss or pulmonary damage within 10 years following cancer treatments (Cheifetz, Park Dorsay, Hladys, MacDermid, Serediuk & Woodhouse, 2014; Howell et al., 2012). Combined with an emerging awareness of their psychosocial needs and the growing number of cancer survivors, the pressure on long-term follow-up oncology resources is concerning (Grunfeld, Julian, Pond, Maunsell, Coyle, Folkes, Joy, Provencher, Rayson, Rheaume, Porter, Paszat, Pritchard, Robidoux, Smith, Sussman, Dent, Sisler, Wiernikowski, & Levine, 2011).

While the traditional model of follow-up care - provided by oncologists at cancer centres - focuses on prevention and detection of new and recurrent cancers, evidence suggests the current systems for follow up care in Canada are not sufficient to sustain the support needs of this burgeoning population (Sperling et al., 2014; Howell et al., 2012; Jefford et al., 2012; Hewitt, Greenfield & Stovall, 2006; Oeffinger & McCabe, 2006; Jefford et al., 2008). Consequently, there is an urgent call to re-organise the current structures for post-treatment follow-up care to ensure sustainability (Sperling et al., 2014; Howell et al., 2012; Jefford et al., 2012).

Unconventional models of care, such as nurse-led follow-ups, have been trialed and are increasingly being implemented in cancer organizations (Howell et al., 2012). In fact, several studies have demonstrated comparability between nurse-led follow-ups and specialist-led follow-ups, for detecting cancer recurrence (Howell et al., 2010). Further, patients were satisfied with this different approach (Howell et al., 2010). With adequate communication and interdisciplinary health care teams, nurse-led follow-up care is potentially the most practical option to alleviate pressures on overwhelmed oncologists (Howell et al., 2012).

To further support cancer survivors in their transitions from treatment, written survivorship care plans have been developed, and consist of “[...] a treatment summary, information on possible late or long-term effects, information on signs of recurrence, guidelines for follow-up care, identification of providers, recommendation for healthy living, and identification of supportive care resources” (Grunfeld et al., 2011, p.4755). While these plans are intended to facilitate transition from active treatment and specialist care to survivorship routine follow-up, studies indicating beneficial patient-reported outcomes are inconsistent. Some literature demonstrates minimal impacts of these care plans, particularly on psychological distress and satisfaction with care, and are proven to be just as confusing for coordination (Boekhout, Maunsell, Pound, Julian, Coyle, Levine, Grunfeld & FUPII Trial Investigators, 2015; Brennan, Gormally, Butow, Boyle, & Spillane, 2014; Sprague et al., 2013; Grunfeld et al., 2011; Howell et al., 2012). Other literature however, demonstrates advantages for survivors following such care plans, including increased knowledge and satisfaction with care, and a greater confidence in their providers’, and their own, expertise in survivorship management (Palmer, Tompkins Stricker, Panzer, Arvey, Baker, Casillas, Ganz, McCabe, Nekhlyudov, Overholser, Partridge, Risendal, Rosenstein, Syrjala, & Jacobs, 2015; Brennan et al., 2014).

In 2007, the Canadian Partnership Against Cancer (partnershipagainstcancer.ca) implemented a national strategy to improve care for cancer survivors and has since initiated pilot projects that evaluate the implementation of survivorship care plans, as well as different models of care (Ung, Souter, Darling, Dobranowski, Donohue, Leighl, & Ellis, 2014; Jefford et al., 2012; Sussman et al., 2012; Howell et al., 2011). Together with a vigorous systematic review these pilot studies informed the development of guidelines for best practices in survivorship care for a variety of health care settings (Howell et al., 2011). Unfortunately, the extent to which they have been implemented remains unknown.

While efforts to support the journey of survivors throughout the continuum of care have been profuse, many gaps in survivorship care continue. Access to coordinated teams who specialize in helping post-treatment survivors and the wide-range of issues they face, is a need that is globally recognized - but remains untested (Howell et al., 2012). Progress will include evaluation of current services and system processes to determine effectiveness, appropriateness and utility.

2.3 Coaching Interventions

Health coaching is a relatively new concept. In a synthesis of the literature, Olsen (2014) defined health coaching as a health-focused, client-centered partnership that empowers the individual to achieve goals. Health coaching is a collaborative process and its objective is to help patients “[...] gain knowledge and problem-solving and coping skills needed to successfully self-manage the disease and its related conditions” (Lanese, Dey, Srivastava & Figler, 2011, p.20). The intent is to motivate patients to acquire and maintain healthier behaviors (Pearson, 2011; Olsen, 2014).

Coaching as a health intervention has been used for support related to chronic health conditions, such as diabetes, as well as to promote physical activity (Bray, Turpin, Jungkind, & Heuser, 2008; Fortier, Sweet, O’Sullivan, & William, 2007). It has only recently been applied with cancer patients, by the ORCF – an innovation in this sector of health services.

Coaches provide self-management support, help set up short and long term health goals, identify barriers and assist with developing action plans to overcome them, as well as provide patient education (Olsen, 2014). Moreover, health-coaching interventions are designed to be flexible and customizable in order to meet the unique needs of each patient (Olsen, 2014). As a result, the structure (eg. frequency and duration) of these interventions varies not only from patient to patient, but across disciplines and contexts (Olsen, 2014). The main attributes of health-coaching

include: Health-focused, partnership, client-centered, goal-oriented, process, enlightenment and empowerment (Olsen, 2014).

Cancer survivors often experience decreased self-confidence, which in turn affects their ability to self-manage the practical, social, emotional and mental issues they encounter as they complete their treatments and enter the survivorship phase of cancer (Wagland, Fenlon, Tarrant, Howard-Jones, & Richardson, 2014). Self-confidence is part of self-management, which is defined as “awareness and active participation by the person in their recovery, recuperation and rehabilitation, to minimize the consequences of treatment and promote survival, health and wellbeing,” (Wagland et al., 2014, p.1). Self-management is therefore an instrumental factor in cancer survivorship, which encompasses various issues that often remain unresolved for years and significantly diminish quality of life (Wagland et al., 2014; Harrington et al., 2010).

In an experimental study by Wagland et al. (2014), the impact of a life coaching intervention was assessed using multiple-item scales, pre and post-test. Particular variables of interest were self-management and goal achievement (Wagland et al., 2014). As coaches helped cancer survivors identify and pursue personal goals, cancer survivors realised that they can achieve many other things (Wagland et al., 2014). Consequently, this form of support enhanced confidence to determine goals, and to pursue them (Wagland et al., 2014).

Coaching interventions help cancer survivors develop the necessary tools and skills to manage the effects of cancer in a way that is sustainable (Wagland et al., 2014; Olsen, 2014). Coaching has been shown to have a positive influence on a healthy transition from treatment to life post-cancer, therefore it has the potential to reduce the severity of post-treatment effects and increase overall health in cancer survivors (Wagland et al., 2014). This evidence indicates that future support services for cancer survivors could benefit from a coaching design.

While the literature implies the benefits of coaching, there is a lack of conceptual clarity due to the various uses of the terms health and life coaching (Olsen, 2014). In addition, existing studies evaluating the effects of coaching have measured specific outcomes, using quantitative analysis. Further studies are needed to evaluate how coaching interventions are lived by cancer survivors, and what are the effects of specific cancer coaching on broader, psychosocial outcomes.

2.4 Summary

The literature review provided in Chapter 2 discusses 1) common issues cancer survivors encounter, 2) what survivorship is and what follow-up care looks like in Canada and, 3) coaching interventions and how they can help cancer survivors. This section provides a synthesis of the current literature that will act as a useful source of knowledge in the understanding and analysis of cancer survivors' experiences with the Cancer Coaching Program. The most significant gap in the literature was the lack of empirically-based programs to help cancer survivors manage the psychosocial effects of cancer. Process and summative evaluations have been limited and there is a need for more detailed explanations of the types of programs available, and the mechanisms that promote positive impacts among cancer survivors.

Survivorship and follow-up care remains inconsistent across Canada and the complexity of the cancer care system exacerbates the burden cancer survivors and their families often have for years. While coaching interventions have the capacity to help, they remain quite new and insufficiently reviewed in oncology settings. The evaluation of psychosocial impacts of a coaching intervention during the survivorship stage of cancer will therefore contribute knowledge to help address the gaps in survivorship, oncology and coaching literature.

CHAPTER 3: METHODOLOGY

The overarching purpose of this research project was to explore the lived experiences of cancer survivors who participated in the Cancer Coaching Program, developed by the ORCF. This chapter discusses methodological aspects of the study such as: Research design, data collection, participants, data analysis and rigor.

3.1 Research Context: The Coaching Intervention

After being matched with a coach, at the initial session (Appendix A) the client begins by filling out a personal log called the *I Can Plan* (Appendix B), which helps them identify their needs and establish personal and health goals (ORCF, 2013). Collaboratively, the client and the coach create an action plan to achieve the established goals. Regular check-ins are part of the program and provide an opportunity for discussion as clients transition to other programs, explore different services and resources, and put into practice the knowledge and skills learned during their participation in the program (ORCF, 2013b). Check-ins take place at the Maplesoft Centre in Ottawa, Ontario or by telephone and typically occur every three months although frequency is based on preference and needs (ORCF, 2013b). A *Check-In Consultation Form* (Appendix C) is used by the coach at every appointment, as well as the *Goal Review Form* (Appendix D), to evaluate client progress and determine any needs for adjustment (ORCF, 2013c).

While coaching sessions are typically private one-to-one meetings, clients can also choose to participate in group coaching sessions which allow them to learn from their peers and support each other in reaching their goals (ORCF, 2015b). A variety of health and wellness services such as curriculum-based workshops, nutrition classes and healing therapies, compliment the coaching sessions and are easily accessible at the same centre (ORCF, 2015a).

The Cancer Coaching Program has evolved since it first started in 2011, when clients could access a cancer coach for one-on-one support, or join any of the groups and programs, on a walk-in basis. At that time, there were over 30 types of group programs offered free of charge, such as: Fitness, Yoga, Nutrition, Arts and Music for Wellness, Positive Thinking, Resilience Training, Coping with Cancer, Work and Cancer, Caregivers, Bereavement, Complimentary Therapies, Brain Fog, Massage Therapy, Acupressure, Lymphedema Information Sessions. In 2012, client intake changed - encouraging all potential new clients to first attend an information session to better understand what Cancer Coaching is, to learn about the ORCF as well as to learn about the different services such as, one-one-one coaching, group coaching (no cost), coaching workshops and healing therapies.

To date, approximately 2,000 families have been coached and according to a Cancer Coaching Client Patient Satisfaction Survey from 2014:

“... 93% agree they are in a better position to keep themselves healthy; 91% agree they are better able to cope with life; 90% agree they are more confident they can do something about their cancer and wellbeing; 87% agree their quality of life has improved; 84% agree they are better able to understand their cancer, and get the treatment that is best for them” (ORCF, 2015b).

3.2 Research Design

Qualitative research aims to gain in-depth and complex understanding of a human or social phenomenon (Creswell, 2012). By adopting methodological and interpretive practices, a qualitative researcher is able to build a complete and truthful representation of reality as it is lived by a set of individuals (Creswell, 2012). Qualitative methodology is considered when there is an issue to be explored more thoroughly, as well as to capture what it means, how it works, how it is

lived and why it matters (Corbin & Strauss, 2015). By shaping this study qualitatively, it allowed insight into the lives of cancer survivors and their experiences participating in the Cancer Coaching Program.

While relatively new, The Cancer Coaching Program is the only one of its kind in Canada at this time. Given the limited research on cancer coaching, a grounded theory approach was selected for this study, to facilitate exploration of the topic in depth and provide empirical findings, which form the basis of a theory to explain the phenomenon of cancer coaching process (Strauss & Corbin, 1990). This approach uses data generated by cancer survivors, who have experienced this phenomenon themselves, to ground the theory in their reality. Strauss and Corbin's (1990) approach to grounded theory focuses on discovering a core phenomenon, and explaining it in terms of its properties such as, the "conditions that give rise to it, the actions by which it is expressed, and the consequences that result" (p.420). While other approaches to grounded theory exist, Strauss and Corbin (1990) was selected because it provides clear guidelines on how to analyze the data and conceptualize a theory. This inductive approach focuses on "unraveling the elements of experience" (Moustakas, 1991, p.4). Studying the interrelated elements, and discovering how they function together, facilitated development of a model which explains the processes involved in a Cancer Coaching Program participation, and the impacts.

3.3 Data Collection

3.3.1 Population

The participants of this study were sampled from a number of clients that have enrolled and participated in the Cancer Coaching Program. Specifically, they were sampled from a population of clients that were in the post-treatment stage of cancer at the time of participation, representing

25% of the program's clients. Table 1 presents an overview of the program's clients, providing demographic details of the sample from which the sample was recruited from.

Table 1. Overview of Population Sample Characteristics Between 2013-2014 and 2014-2015 Clients

Gender	Female	75%
	Male	25%
Age	49-54	29%
	55-64	40%
	65-74	15%
Cancer Stage	Treatment	27%
	Post-Treatment	25%
	Caregiver	24%
Cancer Type	Breast	42%
	Colorectal/bowel	5.5%
	Lymphomas	5.5%
	Other	13%
	No cancer (caregivers)	19%

3.3.2 Recruitment

Following receipt of ethics approval from the University of Ottawa Research Ethics Board on August 28th 2014 (Appendix E), purposeful sampling strategies were used to recruit participants. The recruitment protocol consisted of mailing a recruitment notice (see Appendix F), an introductory letter signed by the Chief Executive Officer of the ORCF (Appendix G), a consent

form (Appendix H) and a demographics survey (Appendix I), to individuals aged between 35 and 75 years, who spoke French or English, had completed curative treatments, and were listed in the ORCF cancer coaching database.

When selecting the list of participants for the recruitment mail-out, the criteria were that they had to have enrolled and finished their participation in the Cancer Coaching Program (ie. now considered to be an inactive client) and had received a minimum of one initial coaching session and two check-ins. Because goal reviews are exhaustive and require more time, the coaches agreed that one goal review is comparable to two check-ins. Thus, individuals who participated in goal review sessions without receiving check-ins, were eligible for the study.

To protect client confidentiality, the ORCF assisted with recruitment by retrieving the contact information of the individuals who met the inclusion criteria from their database. Individuals meeting the criteria were then sent a recruitment letter. Eligibility was confirmed with the demographic survey and by asking participants at the beginning of the interview to confirm the date they completed their treatment regimen and when they initially registered in the program.

Participants expressed interest in the study either by telephone, e-mail, or by returning a filled consent form and demographic survey; after which the researcher contacted the participant to schedule an interview. Participants had a choice to do the interview in person or by telephone. All participants signed a consent form prior to participating in the interview.

3.3.3 Interviews

Data for this research project was collected via interviews, as it is one of the most efficient methods to gain insight and understanding of experiences (Rowley, 2012). Due to its flexibility to probe for additional information when needed (Patton, 2002), a semi-structured interview guide was used. Each participant took part in one, audio-recorded semi-structured interview between 45 and 60 minutes duration, which was transcribed and anonymized. The interview guide (shown in

Appendix J) focused on the role cancer coaching has played in their cancer experience, the assets drawn on to manage challenges in their experience, the cancer survivors' experiences of navigating through various components of the health system, and any gaps in service they encountered. Following each interview, main themes and key issues were summarized in a general memo created by the researcher.

3.4 Data analysis

While it is popular for conventional qualitative methods to collect data prior to systematic analysis, grounded theory analysis typically begins at the very first data collection point (Corbin & Strauss, 1990). In this study, data collection and analysis occurred simultaneously and persisted until saturation was reached (Corbin & Strauss, 1990). To allow this to be a continuous, fluid process, the audio-recorded interviews were transcribed verbatim as soon as they were completed, and were checked by another member of the Resilience and High Risk Populations Research Lab for accuracy. This protocol allowed the team to begin the analytical process right away and to prepare for the next data point.

Following Strauss and Corbin's (1990) approach, three different coding techniques were applied to each data set: Open, axial and selective coding. *Open coding*, or initial coding, is an exploratory process that consists of 'breaking open' the data to discover the main ideas (Van Niekerk & Roode, 2009; Richards & Morse, 2012). During this first level of coding, transcripts were read line-by-line to identify concepts, such as incidents, events or ideas - from which 233 codes emerged (Corbin & Strauss, 1990). After careful revision for duplicates and overall legitimacy of identified codes, 136 remained.

Similar concepts were grouped into seven categories, which are a level higher in abstraction. To ensure these were valid and no important concepts were missed, the researcher coded four

interview transcripts with a team of two research assistants. To further establish rigour in the coding process, my thesis supervisor was provided with memos that described each significant category in detail, with the inclusion of quotations. Writing of these memos provided an opportunity to define the main categories of the study, compare them across participants, and to report on emerging links. Accordingly, a *constant comparative method* was used throughout the analytic process, examining various pieces of data for differences and similarities (Corbin & Strauss, 2014).

After fragmenting the data to identify and classify emerging concepts, *axial coding* allowed for piecing back the data by making connections between the categories and concepts (Van Niekerk & Roode, 2009). This was achieved by developing the properties and dimensions of each category through the use of a causal paradigm model (Figure 2). This was useful in the identification of *conditions* that lead to the occurrence of a particular category, the *actions and interactions* by which it is expressed and in what *context*, the *barriers and facilitators* of those actions, and finally, the *consequences* that resulted (Corbin & Strauss, 1990; Van Niekerk & Roode, 2009). It was through this specification that the categories became denser and gained explanatory power (Strauss & Corbin, 1990).

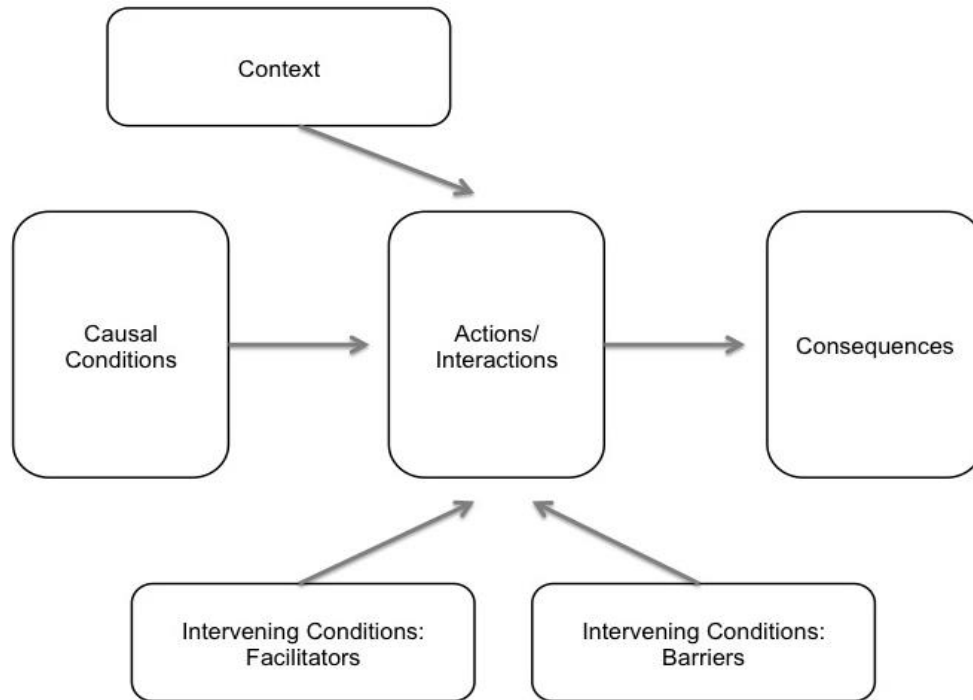


Figure 1: An adapted version of the *causal paradigm model* (Strauss & Corbin, 1990) applied with each category during axial coding.

While relationships between categories were established thorough the process of axial coding, *selective coding* was used to verify these relationships (Van Niekerk & Roode, 2009). This third layer of coding consisted of three steps: 1) Identification of a central phenomenon, 2) use of the causal paradigm model to link categories to the core phenomenon and, 3) verification of these relationships in the data. A core category best representing the central phenomenon of the study was chosen and was linked to all other categories—the conditions, actions, facilitators/barriers and consequences (Strauss & Corbin, 1990). Because the causal paradigm model (See Figure 3) was also used at this stage, it resembled axial coding (Van Niekerk & Roode, 2009). What was different at this stage however, was, rather than developing each individual category, categories were unified to develop a core phenomenon (Strauss & Corbin, 1990). Asking questions such as: “What is the main analytic idea presented by this research? If I had to conceptualize my findings in a few sentences, what would I say? What does all the action/interaction seem to be about?

How can I explain all the variation that I see between and among the categories?” helped identify the core phenomenon (Strauss & Corbin, 1990, p.424). This phenomenon and how it evolved were discussed in-depth with my supervisor, and concrete examples from the data were used to verify its representation of the lived experiences of the cancer survivors.

At this later stage of analysis, rather than dismissing a hypothesis that occurred on different conditions - or simply did not occur - the range of variation provided explanatory power, and strengthened the phenomenon in question (Strauss & Corbin, 1990); increasing the theory applicability in practice (Strauss & Corbin, 1990).

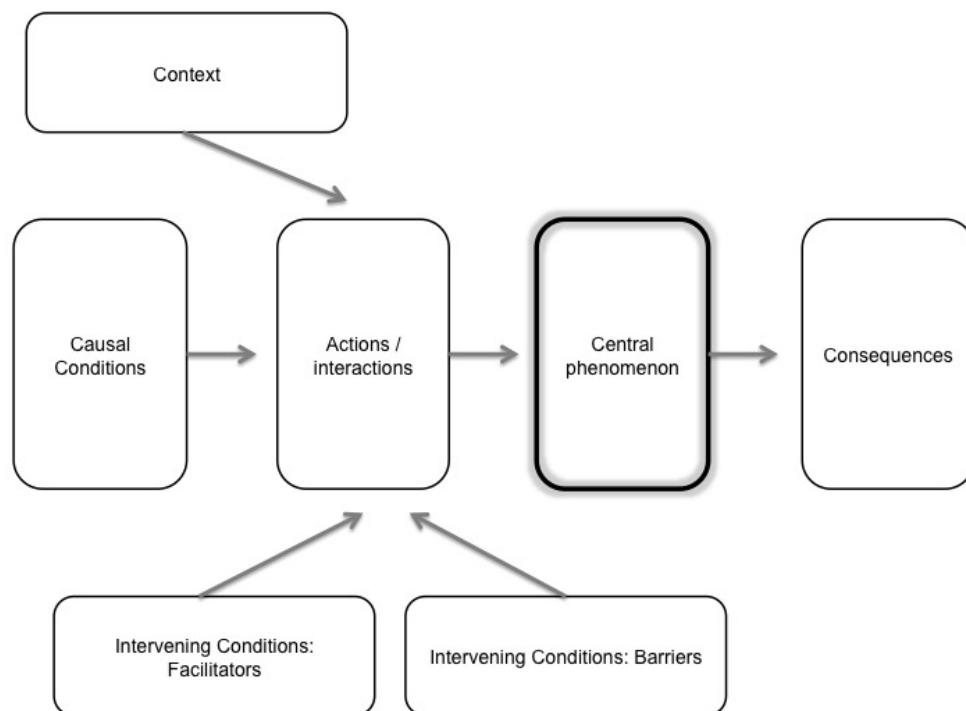


Figure 2: An adapted version of the *causal paradigm model* (Strauss & Corbin, 1990) that linked the categories to the central phenomenon in the selective stage of coding. This model was used to describe the theory.

During the process of *theory building*, patterns were conceptualized and relationships developed with the causal paradigm model. The model was required to fit each case, therefore it was modified until every gap was filled and saturation was reached (Van Niekerk & Roode, 2009). Combined with memos written by the researcher, the model was used to write the analytical storyline - the theory (Van Niekerk & Roode, 2009).

3.5 Data Quality & Limitations

Qualitative studies take place under real circumstances and affect real people, hence their conclusions must be judged to ensure they meet a standard of quality (Miles & Huberman, 1994). Qualitative research encompasses a variety of methods however, and all cannot possibly be evaluated the same (Corbin & Strauss, 1990). To appropriately judge a research study, the evaluation criteria must be specific to its research methods. Consequently, Corbin & Strauss (1990) described 11 canons and procedures to use as the basis for grounded theory evaluation. The following sections explain how this study meets those criteria (Strauss & Corbin, 1990):

- 1. Data collection and analysis are interrelated processes:** As explained in the Methods section, data was collected and analyzed systematically and sequentially. Analysis persisted throughout the study, beginning at the very first interview, continuing during and after data collection. The continuous interplay between analysis and collection of data is crucial in grounded theory and was ensured by rapidly starting analysis when data was collected. The analysis of each transcript generated questions that influenced the next interview, by incorporating new aspects that were relevant.
- 2. Concepts are the basic units of analysis:** While building the theory, data were conceptualized by giving incidents conceptual labels during the coding process. When incidents represented the same phenomenon, they were regrouped under the same label. For

example, if a participant described feeling confident at work and in health decisions, being able to take on favourite activities again, feeling dedicated to improving health habits, or comfortable talking about personal experience, etc., this piece of data was labeled as “empowerment”. Many concepts were derived from this process, however it was only by repeatedly appearing in the data that a concept gained relevancy and secured a place in the theory.

- 3. Categories must be developed and related:** Categories are the “cornerstones” of theory development and are a higher level of abstraction (Corbin & Strauss, 1990, p.7). To obtain them, concepts that referred to the same phenomenon were grouped together. It was important to group concepts together because they represented the same phenomenon; not because they appeared to be similar. For example, in addition to the concept of “empowerment”, other concepts such as “self-reliance”, “participation” and “networking” pertained similarly to positive actions that were prompted by the coaching. They were then grouped under a more abstract heading “Coaching Consequences”. Corbin and Strauss (1990) explain however, that grouping under a more abstract label does not make a category; rather, it must be defined. It is through axial coding then, that the conditions, context, facilitators, barriers and consequences were defined for each category.
- 4. Sampling proceeds on theoretical grounds:** As mentioned in the Methods section, theoretical sampling was not feasible for this project. Given the labour-intensive process of identifying eligible cases within the ORCF database, it was not possible to continually modify the recruitment criteria before the next data collection.
- 5. Analysis makes use of constant comparison:** During analysis, incidents were compared for similarities and differences within the data generated by each participant, as well as across the complete data set. Comparisons were made during the coding process (including all three

coding procedures), as well as in a comparative table to clearly illustrate the differences and similarities across data sets and main concepts.

- 6. Patterns and variations must be accounted for:** Every participant experienced cancer differently and had a unique story to tell. Patterns emerged during axial and selective coding, as relationships developed. Both patterns and variations were used to elaborate the theory, giving it explanatory power. For example, coaching sessions provided support for cancer survivors however, the type of support received varied from one participant to another, as the coaching was entirely tailored to their needs. The variations were responsible for giving the theory essence.
- 7. Process must be built into the theory:** Grounded theory does not only describe a phenomenon, it develops its properties and conditions, and explains them. This resulted in the dissection of cancer survivors' experiences with the Cancer Coaching Program, as a process which began with their completion of treatment, their participation in the program, and post-participation to their current states.
- 8. Writing theoretical memos is integral to grounded theory:** Memo-writing was used throughout the study as a tool to track relevant ideas about the data, including concepts, categories, patterns, and comparisons. Memos provided a platform to write out any thoughts about the data and in fact, were an integral part of the analysis. The memos were consulted during development of the theory, as they proved to be useful in providing conceptual details.
- 9. Hypotheses should be developed and verified as much as possible:** Many assumptions were made regarding relationships between categories, and were verified throughout the analysis, to establish whether or not they were significant. Each category was defined during the axial coding phase, and all categories were related together during the selective coding

phase. Also hypotheses were continually checked when returning to the field to collect more data. Further, these were verified and modified according to feedback from my supervisor.

10. A grounded theorist need not work alone: To ensure this work remained credible and there was minimal bias, regular meetings with my supervisor and colleagues were used to test out main ideas. Collaboration increased theoretical sensitivity and offered different perspectives. Expressing concerns and thoughts aloud helped achieve clarity and resulted in many “a-ha” moments.

11. Broader structural conditions must be analyzed: Broader conditions other than the ones directly affecting the phenomenon were considered during analysis. For example, the socioeconomic status of participants, work status, if participants had applied for long-term disability, or if they had sick-leave accumulated or had encountered financial issues. Another example of a broader condition considered by the researcher was the living situation of the participant. These were not simply noted in the analysis, but rather linked to the core phenomenon, considering their influence on the process.

Strauss and Corbin’s (1990) canons and procedures provided clear guidelines in how to conduct this research. As demonstrated in this section, they were followed as closely as possible to ensure a credible grounded theory study. While it was a priority to increase the authenticity of the study and prevent bias, researcher personal traits, experiences and perspectives inevitably influence collection and analysis of the data.

CHAPTER 4: RESULTS

4.1 Participants

A total of ($n=12$) participants volunteered for the study, out of 138 eligible individuals. Each interview was conducted by phone, with the exception of one participant who chose to do the interview at the ORCF. Table 2 presents a summary of participant demographics, including type of diagnosis, age, current employment status and living situation. Current employment status was requested to identify whether they had successfully returned to work after treatment, whereas information on living situation was asked in order to assess what support was available from home. All participants received at least one initial conversation and either two check-ins, or one goal review. The earliest participation was August 2012 and the most recent was October 2015. The mean age for this study was 61.4 years. The sample consisted of ($n=4$) males and ($n=8$) females. Of the 12 participants, four were currently employed and five lived alone. The majority were survivors of breast cancer, however there were also survivors of colorectal cancer, uterine cancer, esophageal cancer and leukemia. All participants had completed curative treatments and entered the survivorship stage of their cancer when they signed up for the Cancer Coaching Program, with the exception of three participants. The first was diagnosed with incurable leukemia and was not eligible to receive treatment; the second was receiving palliative chemotherapy, and the third registered for the program after being diagnosed, but continued coaching throughout the survivorship stage. Although the inclusion criteria of having completed treatment regimen was not met for two of these participants, the chronic nature of the diagnosis, an unfavourable prognosis, and most importantly, the value these individuals attributed to the program, influenced the decision to include them in the study.

Table 2. Participant Demographics

	Age	Sex	Cancer	Employment	Living Situation	# Coaching Sessions	Phase	Time of Participation
1	71	F	Breast	No	w/Spouse	I + 3 check-ins	Survivorship	Aug 2012 - Jan 2014
2	63	F	Breast	No	Alone	I + 3 check-ins	Survivorship	Aug 2013 - Jan 2015
3	63	M	Colorectal	No	w/Spouse & children	I + 2 check-ins	Survivorship	Nov 2012 - Nov 2013
4	55	F	Breast	Yes	w/Children	I + 4 check-ins	Survivorship	Oct 2012 - Dec 2013
5	58	F	Breast	No	w/Spouse	I + 2 check-ins	Survivorship	Oct 2012 - Nov 2013
6	42	F	Breast	Yes	w/Children	I + 1 goal review	Survivorship	Oct 2013- Dec 2013
7	65	M	Leukemia	No	Alone	I + 4 goal reviews + 2 check-in	Diagnosis	May 2013 - June 2015
8	57	F	Uterine	Yes	Alone	I + 4 goal reviews + 1 check-in	Survivorship	Mar 2014 - Apr 2015
9	64	F	Breast	No	Alone	I + goal review + 2 check-ins	Survivorship	June 2013 - June 2014
10	64	M	Esophageal	No	w/Spouse	I + 2 goal reviews + 1 check-in	Palliative Tx	Jan 2015 - Oct 2015
11	67	M	Colorectal	Yes	Alone	I + 3 goal reviews + 1 check-in	Survivorship	May 2014 - Oct 2015
12	68	F	Breast	No	w/Spouse	2 I + 3 check-in	Diagnosis & survivorship	June 2013 - Oct 2015

“w/”: With, “I”: Initial Conversation, “Tx”: Treatment

4.2 Findings

In accordance with Strauss and Corbin's (1990) approach to grounded theory, Figure 3a represents the key findings of this study in a *causal paradigm model*. This model encompasses the experiences of 12 participants and illustrates the coaching intervention as a process.

The starting point of the model represents the beginning of the coaching program where *causal conditions* (point A) such as post-treatment issues, specify the reasons why support is needed from the program. According to those conditions, the cancer coach and the participant will initiate specific person-centered and solution-focused *actions*. With the implementation and maintenance of these strategies, cancer survivors progressively gain the confidence and self-reliance necessary to manage the conditions identified at point A. It is at this point we recognize the program's role of 'bridging the gap' between problematic post-treatment conditions and positive *consequences* that include successfully managing the multidimensional effects of cancer, finding a new 'normal' and re-integrating into daily life (point B). The model also includes *facilitators* and *barriers* that either enhance or impede the coaching experience – these facilitators and barriers stem from multiple levels (eg. individual, program, community).

While every participant and their experiences were unique, saturation was reached as the core phenomenon of the study "bridging the gap" appeared across all data sets.

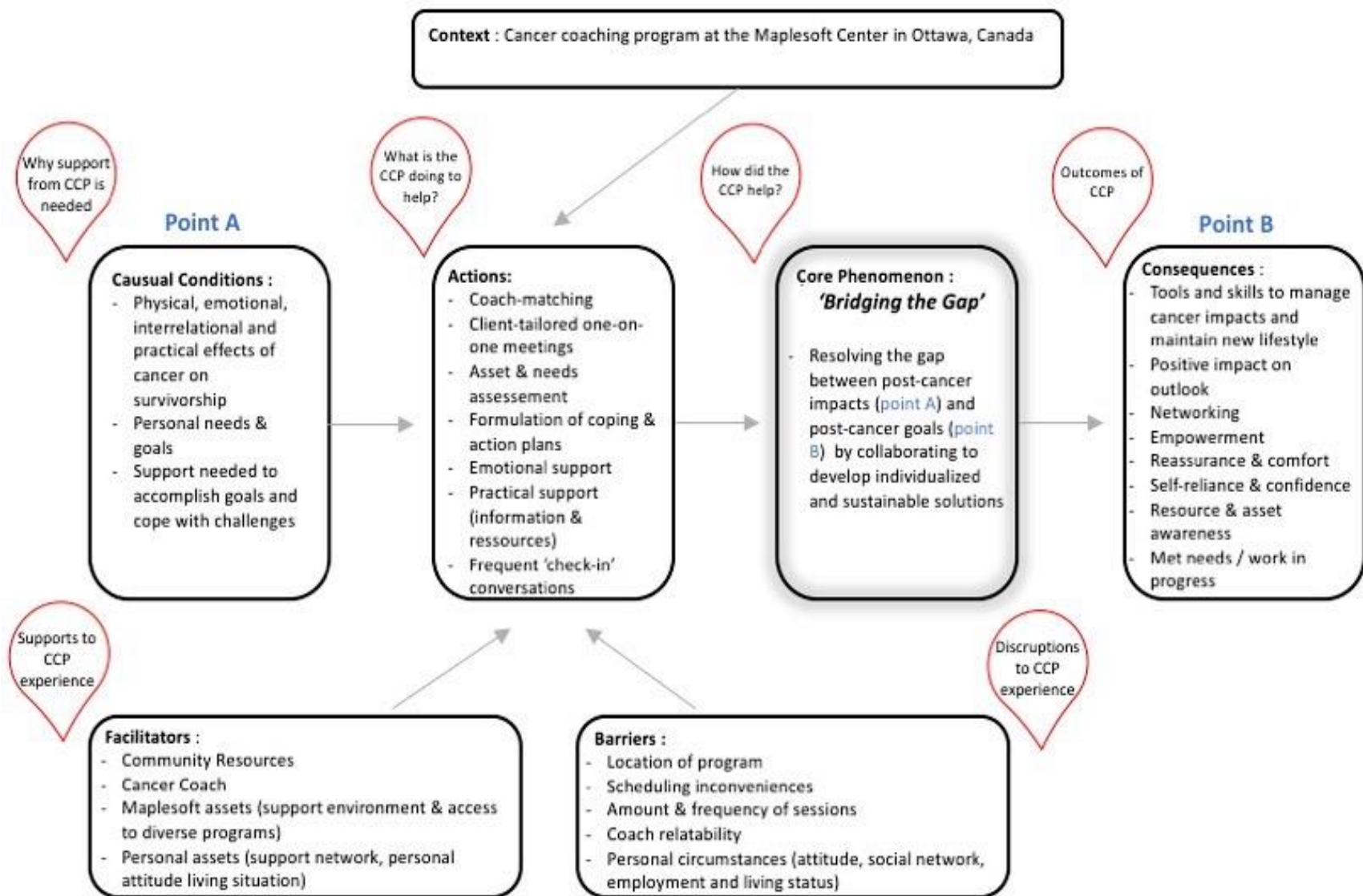


Figure 3a: An adapted *causal paradigm model* (Strauss & Corbin, 1990) portraying the Cancer Coaching Program experience

4.3 Causal Conditions

The findings in this section represent various reasons why support from cancer coaching is sought by cancer survivors; as determined by the numerous challenges they must face, their personal needs, as well as the goals they want to accomplish.

4.3.1 Impacts of Cancer and Survivorship Challenges

Cancer affects life on physical, emotional, interpersonal and practical levels, at every stage of the disease; each presenting different issues. As such, the survivorship stage of cancer involves its own challenges. In fact, the transition to becoming a survivor and returning back to ‘normal’ is a challenge in itself. While the majority feel relieved at the time they are declared ‘cancer-free’, separation from hospital care, persisting side-effects and re-integration into daily life, can become overwhelming:

“So then when I was into the survivorship, it was just scary and alone and you know, the anger because then I was thinking back like why did this happen to me, I’m so young. A lot of reflection ... it was very difficult for me. I just felt like I was, you know, thrown back and kind just left to kind of, just deal with all the emotions and well, ‘what does this mean’ and, I, I had a lot of anxiety about the thought of recurrence...” (P6)

Within these poignant emotions, the feelings of being lost and alone often result from less contact with medical professionals; this differs from the frequent meetings during the acute stage. Having minimal contact with a cancer professional, combined with persisting side effects, causes many people to fear recurrence of the disease:

“[...] when you go into the cancer process you know, the chemotherapy, the nurses coming in after you get the chemo, and then you go into the radiation and to have that cut cold turkey, for nobody to contact you [...]. Because all of the sudden the ship has sunk and you’re out there by yourself and so, what do you do now? Because you were looked after so well...” (P2)

“When you’re going three or four months without seeing a doctor, you sort of think ‘oh you know’, you sort of worry about if you know, everything’s being—you don’t have that check-in, you know, point with somebody that you feel is knowledgeable

and say 'everything is well' and that, and everything, so. And your body is still trying to more or less get back, get back to normal (laughs) what's the new normal I guess." (P5)

"I mean I was certainly quite, quite happy in the sense that you know I was through all the treatments and, and that, and it's—at the same time you're not seeing the doctor you know, all the time or as frequently so there's a bit of fear there [...]. So it was sort of relief but at the same time there's always the fear at the back of the mind, 'maybe it'll come back, maybe they didn't get it all' or that sort of thing, so." (P5)

In addition to a myriad of emotional difficulties, the recovery from cancer has a number of practical effects on daily life. Indeed, this impacts the survivor's ability to adjust to post-cancer life. Participants described the challenges of re-integrating into their routines such as going back to work, as well as finding their 'new normal':

"One of the main issues which was, as a patient you are coming from a really rare disease, cancer and then how do you do get back to your normal, specifically your job, to go back to working [...]. I didn't go back to work because it took so long so that they terminated my contract. So that also brought a lot of emotional distress." (P3)

"Especially to help you with how to express yourself to your employer [...]. You're not looking for sympathy. But you don't want them to forget either that you have these symptoms and this is your new normal and that you know, my new normal isn't the way I was before." (P6)

"[...] but I realized even when I was through all the major treatment that I didn't have the energy to do the job that I had been doing. And you know I still, still miss it to a certain extent and trying to find a focus in my life and that. And that's an on-going adjustment. Because I had planned to be working you know." (P5)

Participants also mentioned the financial impacts of having cancer, having encountered other survivors with financial difficulties. Although the participants mentioned they personally did not have to face financial problems, the recurrence of this particular issue within their network, indicates it is an important problem for this population:

"A girlfriend of mine had just started with (name of workplace) and she got breast cancer but she hadn't been there for very long and didn't have leave accumulated. She's had to go through the long-term disability and she said it was an absolute nightmare [...]. If you're not expecting that and a lot of people don't have a nice big

cushion put aside, it puts a—you know, you're dealing with the illness and what it's doing to you physically. You really don't need to have the financial pressures put on you. And I've been dealing with some of the other cancer survivors, not just from breast cancer but cancer in general from Maplesoft, you should see and hear about these people struggling.” (P4).

“Ok, some of us do have insurance, we're fortunate – others don't. And even if you do have insurance, everything had a cap. But when you're going through cancer, and you have no way to get out and get groceries and you can't do this and that, it costs a lot, it costs a lot for drugs, it costs a lot for, even for some people for the programs that are offered at Maplesoft centre.” (P2)

Furthermore, physical side effects from cancer treatment and surgery - that persist into the survivorship stage - also impinge activities. Extreme fatigue, memory loss and hormonal changes, are common physical issues cancer survivors cope with:

“[...] j'étais fatigué, vraiment j'ai mis, j'ai mis presque deux ans à devoir dormir entre dix-huit et vingt heures par jour [...] c'est à peine si je pouvais me tenir debout dix minutes à ce moment-là. J'étais tellement épuisé [...] quand qu'on est toujours fatigué et t'as besoin de dormir et puis on n'a pas de conversation courante avec nos amis, c'est toujours 'mais qu'est-ce que tu fais ?' bien je dors. ” (P1).

“I have some physical stuff going on you know from the radiation. Some nerve damage from the surgery. So there's a little bit of pain there. It's affected my relationship; my hormone therapy has affected my relationship because my libido has gone way down [...]. I have a lot of fatigue from, from the hormone treatments as well as the after-effects of radiation, I'm still really tired. And that slows me down a little bit. The hormone treatment also affects my cognitive so my memory isn't as good as it used to be.” (P6)

Participants also discussed the particular challenges of having certain types of cancer. For example, a breast cancer survivor revealed the struggles of having a prosthesis:

“I had [one] but it was more a pain in the butt then anything...But as soon as I came home that darn thing came off (laughs). Yeah, and I was fine. It never bothered me being lopsided but it was hard on my body. And it was hard to just get clothes to fit properly and you have to find different styles and that was more awkward and trying to find support for that remaining breast without having to wear a prosthetic so trying to find sport bras or different kinds of things that work.” (P4).

Social issues were impacts reported frequently by the participants in this study. One cancer survivor expressed feeling the need to be cautious at work - to avoid making colleagues

uncomfortable with her cancer experience; others described experiencing minimal compassion from their family and friends:

“I wore it, I wore it for work because I deal with a lot of external clients and a lot of men and they didn’t need to know what I’ve gone through, I didn’t want to make them feel uncomfortable.” (P4)

“Et puis ce que j’ai trouvé dans l’interaction avec les gens, ce que j’ai trouvé le plus pénible c’était réellement qu’on me disait que j’avais rien. Que ce n’était pas grave et puis, tu sais la radiation mais, y’a rien là, l’expression, et un moment donné à un party de femme, on me disait ‘ah ça c’est rien, t’as rien, t’as—’ donc j’ai ouvert ma blouse et puis on a vu que le côté de ma poitrine était complètement une plaie vive...Non. Ça m’a dérangé, ça m’a agassé, mais [...]. Finalement, un manque de compassion c’est assez courant.” (P1).

“I wanted some sympathy and like my niece said to me when I was first diagnosed ‘oh you’ll be just fine, if I had to have that or diabetes I’d rather have leukemia than diabetes, people live years for that. I know somebody who had that and they lived 20 years and no problems.’ ” (P7).

Social isolation was also indicated as an important emotional challenge by one participant, which influenced his friendships and ability to receive support:

“I would say that the biggest challenge was the emotional effect that it took and it manifested itself in a lot of ways. Withdrawal from the social situation was one. It was very hard on friendships. That was the biggest challenge. Many people don’t like to talk about this, so for friends it’s hard to talk and hard to discuss it, so if you ask anybody they’ll say it was really hard to talk and sometimes I just didn’t want to talk to people about it. The emotional effect was primarily to withdraw.” (P11)

The impacts of cancer are thus multi-dimensional, affecting individuals on emotional, physical, practical and social levels. Although at survivorship the disease has been clinically treated, the effects are long-lasting; some persisting years after treatment completion. The numerous challenges presented here are indicative of this population’s need for support, and portrays important discrepancies in the continuum of cancer care, particularly around survivorship support services.

4.3.2 Personal Needs & Goals

As every individual is unique, every cancer experience is as well. Cancer survivors have very specific needs and goals they would like to accomplish. As such, cancer survivors seek support from the Cancer Coaching Program for various reasons. In fact, many seek help with their return to work, while others require help with their health habits and lifestyle; still other survivors seek guidance and emotional support from the program: *“That was key for the coaching because I was going back...for me it was helping transition, figuring out my way into going back to my employment.” (P4)*

“Oh just mostly some fears that I had and ... I think I just was afraid because I never thought I would get cancer and then when you get it you start thinking you know, you’re gonna get it again and you’re gonna die. And so I had a lot of questions about that and, and I also wanted some recommendations on how, how I could change my eating habits or my, my health habits to you know, to sort of get your body in a better shape and eat better to prevent cancer from coming back again.” (P8).

“[...] I needed someone to listen to me. I felt that I wanted some [...] well I needed some sympathy. I don’t know why I felt that way, [...]. But I felt I needed somebody who understood me and was willing to sympathize with me a little bit what I was going through. And the pain I was going through.” (P7)

Support needs vary across cancer survivors, as the challenges associated with cancer are diverse. Consequently, it is vital that individual needs be at the focus of support interventions. The Cancer Coaching Program prides itself in providing patient-centered care, tailoring its approach in accordance to individual needs; and this was important for the survivors in this study.

4.4 Actions

4.4.1 The Cancer Coaching Approach

By delivering coaching through different approaches, the Cancer Coaching Program has been able to tailor support for survivors. Indeed, the program has developed both, one-on-one and group approaches to coaching; this optimizes the breadth of cancer coaching support. Naturally,

some survivors preferred the option of receiving coaching one-on-one, while others benefit from being in a group:

“[...]it was too large a group, whereas the cancer coaching is one-on-one and so it’s, it’s geared to you, because everybody’s different, and everybody’s needs are a little different you know, muscles cramps they don’t – I mean, they’re not great but they don’t really bother me that much and you know, somebody else they did bother or they had a lot of hot flashes and that really bothers them. Everybody’s different and the cancer coaching, because it’s one-on-one, it’s personalized.” (P5)

“So we shared tons of stuff amongst ourselves. What we were experiencing and you know, like, I hadn’t gone back to work yet. I was—I’m getting ready to go back to work but some of them had already you know, gone a couple weeks, or they were six months in, or they were a year in. So that was awesome. Like having the—being part of the program with all the other cancer survivors, that was, that was really good. But that was my only interaction with all the other cancer survivors.” (P6).

Specifically, the program ensures person-centered care by allowing the client to lead the coaching sessions. By asking the right questions, coaches give clients an opportunity to reflect on their needs, to establish personal goals and to navigate the course of the sessions. In collaboration with the coach, the client is able to find the appropriate solutions, to learn how to self-manage, and to try new strategies. For instance, this participant portrayed the partnership between him and his coach:

“And her approach was you know, how can we help you? What can we do here to help you or whatever, and I said the thing about diet, maybe nutrition and then we went through the courses and what courses might take, oh this one probably wouldn’t apply that well because you know, this was for something else. Some of it is for, like some of the groups, one might be breast cancer, one might be for people who’ve gone through treatment and they need support after, but for whatever reason, they didn’t apply to me. So we would, we would try to pick the things that would be the best fix for me.” (P7)

This statement reveals the effort to center the coaching sessions around the patient’s needs, by asking the participant specifically how they want to be helped. Not only is this a technique to ensure sessions are patient-centered, but coaches also use this opportunity to perform an asset

and need assessment, to better understand the individual's circumstances. Similarly, one participant describes being asked questions and having the opportunity to reflect on her needs:

“ We had a couple of telephone conversations just like we're having now and we set the goals together, I think I saw her in person before setting up our goals and then she would touch base every couple of months to see how I was doing and to see how we could tweak things [...] it was interesting because they pose questions, they're not—they don't just solve the problems for you, they ask the right questions, they make you think, because this is all about you and you are recovering and not them so they're there to help you along the way and just giving you that guidance and support and they make you think. I think that was one of the main things, just asking the right questions to make you think about what you would want [...]” (P4)

In this participant's statement, there is mention of telephone conversations; referring to 'check-ins' in the program. These are a common strategy used by cancer coaches, to maintain contact with their clients, to provide continuous support, and to reassure their clients, and to assess progress. Moreover, participants described the specific actions taken to help with their personal goals, such as looking for employment and changing their lifestyle:

“They helped me very, very strongly over there. I had a lot of sessions with the coach and she actually set me so much in getting local services, dealing with-- to look employment for people, revising resumes, sending letters and then seminar. They assisted very very much.” (P3)

“[...] two topics that we mostly talked about were eating habits and exercise. Because I'm overweight and have been overweight all my life [...] So we talked a lot about those two things because I wanted to get more fit ... so we talked a lot about how to change your eating habits and what a healthy after-cancer diet is and the research that they've done on that ... And we talked a lot about exercise because after I had the surgery, of course I wasn't exercising much and then I was kind of afraid to get back into exercise. We talked about the different options of getting back into exercise slowly and, and walking, and she told me about some of the things that I could look into that would be better suited to my body type and my age.” (P8)

From these statements, it is clear that providing practical, concrete solutions is a tool used by cancer coaches to meet the needs of their clients. Another approach developed by the CCP is coach-matching. This matching process, which is further explained in section 1.2, is a useful technique to ensure the coach's expertise aligns with the client's needs:

“[...] I filled out a questionnaire there that was all to do with your emotional health and your concerns and your worries and that, that was what they used you know, to match you with the person who would be your coach and I thought that was very useful and I think they did a really good job—I mean I don’t know who the other coaches were because I only dealt with one but I thought she was very well-matched to the areas of concerns that I had indicated on my questionnaire.” (P8)

In summary, the Cancer Coaching Program provides tailored support by using a variety of strategies that ensure individual needs are at the center of the intervention. The Cancer Coaching Program’s approach to tailored care is delivered through two types of sessions, and is facilitated by coach-matching, collaboration, asset-mapping and customizability.

“And I mean, if somebody needed more time or more nurturing, they’re there for you. [...] that’s what they’re there for, if I needed more, they would’ve offered me more but I didn’t so—it was nice that they can customize for each person as required. [...] there’s no cookie-cutter approach because we’re all individuals, we all need different things and they customize it for you which is wonderful.” (P4)

4.5 Facilitators

While the Cancer Coaching Program supports cancer survivors using diverse strategies, there are certain intervening conditions that enhance the coaching experience. This section presents community resources, program aspects and personal assets that were useful to cancer survivors during their participation in the program.

4.5.1 Community Resources

The Cancer Coaching Program prides itself in having a multidisciplinary approach to care, however its role is mainly to support and navigate. Specialized health care services, such as psychotherapy and physiotherapy, are left to the expertise of professionals. In this case, community resources are extremely helpful for clients who are in need of such services or other types of support. Cancer coaches refer their clients to other resources quite regularly, and work collaboratively to identify helpful and available resources in the community. As cancer survivors

highlight additional resources, it allows cancer coaches to broaden their scope of knowledge and most importantly, provide guidance.

“Because I knew that I would be heading back to work so she helped me you know, devise a couple different things and setting up a transition plan and those kinds of things. [...] unfortunately my HR at work are kind of useless. Because I asked them to help me set up a transition plan and they said ‘well no, you have to figure that out’. I thought that was a little short sighted. So I didn’t—and it wasn’t up to (name of coach) either to figure something out because she didn’t really know my physical abilities so I ended up working with my physiotherapist from (name of place). (P4)

“Well, I guess what it did for me is that they gave me the required information that I needed to, to contact different I could say, physiotherapists that I needed. And as a result going to the physiotherapist, it has helped me immensely, it has provided me with exercises to, you know, assist my getting back to normal” (P2).

One participant described cancer coaches as being supportive yet, unable to meet his profound psychological needs. The coach then referred him to professionals specialized in providing that type of support:

“So they would help you set up a personal goal. In my case, my personal goal was to walk and exercise. I think those sort of things were useful, but I needed more help. [...] And she admitted, [...] that she just wasn’t qualified to give that kind of help.” (P11)

Other survivors did not seek specialized services but rather, support from different groups in the community:

“It’s at the (name) United Church, like every support group, this is the support group for leukemia. And there’s a convener and actually, this month, I’m a bit shy, they’re gonna have the candle lighters at the end of October they’re having a walk for leukemia [...] but somebody in our support group has invited us to their cottage in August and we can swim and go canoeing and everything.” (P7).

In all, community resources help cancer survivors with specific issues and provide them with in-depth support. In turn, these resources enable coaches to successfully help their clients navigate along the continuum of survivorship. Community resources facilitate the coaching process and

enhance cancer survivors' experiences with the program. Consequently, survivors benefit from an increase in self-reliance, as well as an increase in resource awareness.

4.5.2 Program Assets

There are various elements that make the Cancer Coaching Program successful at supporting cancer survivors. First, the environment in which it takes place - the Maplesoft Centre in Ottawa Ontario - reinforces the coaching experience. Participants described the Maplesoft environment as versatile, supportive and warm, in which they felt safe to be vulnerable and share with others:

“Maplesoft provides a safe, supportive environment where you are not afraid to open up your heart and to expose yourself. Some people find that very scary but it's such a warm, supportive environment. It takes that edge off and allows you to open up and share [...] Opening up something that is very personal in a very safe, warm, loving environment is key. And that's something you get at the Maplesoft. Where you're not isolated, you don't feel that you're all alone, that no one else is going through the same things that you're going through [...] Having that safe environment where you can actually let down your guard and share and cry together, and it's ok.” (P4)

“Well, when I was telling my aunt about it, I was telling her that you go in, and it's like this, it's like a business but like a home and they have these really awesome de-stressing rooms that you can go in and, they have a kitchen so you can learn how to cook properly, a nice fireplace and the people there are really nice - it's a very relaxing and welcoming environment. And that was huge for me. You know, you get enough of the clinical look, the clinical field [...] that serenity room that they have downstairs. [...] It's this room that you book – I think you can book it a half hour at a time and there's different kinds of like relaxing music and there's a platform that you can lie on and it has like a heating pad or a vibrating pad. [...] and then you can-- there's visuals that go up on the walls and on the ceilings. You can do like an aquarium [...] Yeah it's a very—total sensory relaxing room. It's awesome.” (P6)

Moreover, one participant noted the contrast between the Maplesoft and the clinical environment; she felt there was no time pressure to discuss personal issues:

“I think it's because so much of what you're doing when you're going through treatment is very medically focused and this is an opportunity to deal with some of the other aspects [...] the nurses and the doctors are very good but they're dealing with the most critical parts, the more pressing things the cancer coaching there's more time to discuss some of the softer issues and concerns [...]” (P5)

For some, the Maplesoft environment felt like home, whereas others associated the centre with healing: *“So the next part is to survive and that part would be the Maplesoft Centre where you go to heal shall we say”* (P2). The Maplesoft also prides itself in being a multi-disciplinary facility, offering a variety of courses and workshops:

“[...] they have other people there that can help, not just for her but for the family and they offer such a complete program and all kinds of services’ I didn’t need to avail myself of all of them but it’s just an amazing facility and it’s the first thing I tell people as well as they’ll help you with the transitioning to work, they’re there if you need help with a psychologist, if your kids are having trouble going through this, there’s all kinds of people that you can talk to [...] It’s an amazing facility so I definitely tell people to go there and avail themselves with everything there, whether it be spiritual, physical, mental, exercise programs, yoga, everything, it’s just an amazing facility.” (P4)

“I’ve never needed something that they haven’t been able to deliver on. They’ve been there for me. I did for example, Nordic walking. I was trying to build up my strength again. They have everything there to help you get back into a normal life.” (P12)

Moreover, location and scheduling of coaching sessions proved to be convenient, causing a positive experience with the program:

“That’s another thing, because I am still working full-time, I, I couldn’t go to cancer coaching during the day. And so I was very, very appreciative of the fact that they offer evening cancer coaching as well. Because otherwise I wouldn’t of been able to go—well I’m sure I could’ve taken the time off work you know, but it was really convenient to be able to in the evenings.” (P8).

While the Maplesoft Centre environment facilitates positive effects of the Cancer Coaching Program experience, another significant influencer is the cancer coach. Participants reported specific characteristic of the coaches as the main reason for their positive experience. Some discussed personality traits, while some elaborated on their accessibility and specific skills:

“I just think she’s so good and so easy to talk to [...] sometimes there were things that I wanted to ask her about sex or something that were kind of embarrassing but you know—she was so easy going about everything [...] because I said ‘oh here, here’s this stupid question you know’ and she said ‘no, nothing is a stupid question you know’ and so she was very good at answering any questions I had and putting me at ease about any concerns I had.” (P8)

“I always felt comfortable with her, I could feel very open, confident in her abilities, her sincerity. I can’t think for anybody else but for me she was amazing and I just thought I could talk to her about anything [...]. That openness was awesome.” (P4)

“Now regarding the coaching staff, anytime I had a problem, I had concern, I call them, they were really at my disposal – myself, I’m speaking as a patient, myself, they would answer my question, if they need for me to go there to discuss, I would go there to discuss one-on-one and then they would find the solution to how I can handle the problem of concern.” (P3)

Finally, participants described the Cancer Coaching Program as being not only helpful to them, but for their caregivers as well. While the impacts of cancer extend to family and friends, the programs and workshops at the Maplesoft designed specifically for their support, including individual and group coaching, were proven helpful:

“It was very useful for my wife. The support group. When you have cancer, you have it. That’s it. You learn to live with it. If you’re the person that doesn’t have it... I think it’s a lot harder. I mean it’s not harder from a medical point of view, but it’s a lot harder emotionally. [...] I think it was very useful as a group, for my wife.” (P10)

“I also wanted to involve my husband at that point and so when I had sessions, he would go too. [...] But, anyway, he got so much help from being able to talk about what he was feeling, and for me that was a really important part [...]. They gave him some techniques and some ideas about what to do.” (P12)

In fact, for this particular participant, this accounted for the most important outcome of her coaching experience. When asked what was the most important outcome from her cancer coaching experience, she replied: *“It would be the support that my husband and I got as a couple. For just dealing with the stress of having cancer” (P12)*

4.5.3 Personal Assets

Despite the important influence of cancer coaches, the Maplesoft environment and community resources, survivors identified assets that impacted the way the cancer coaching took effect. Indeed, one’s personal circumstances, attitude and support network, can facilitate positive

coaching outcomes, as well as influence the impact of their challenges. First, participants described the important role their support network played in their lives post-cancer:

“So, and as I’ve said they’ve just bent over backwards for me, accommodating me. I work early hours, I work six a.m to 2 p.m because I’m better in the morning. So, they let me adjust my hours so I can go home and take a snooze before the rest of my family shows up for diner. [...] But they’ve been giving me some of the quieter files to work on and I can be the second person of our projects so that somebody else can be the lead and deal with most of the issues. [...] So I was very fortunate because I did have support from work and I was just able to manage [...]” (P4).

This participant was coping with physical side effects therefore, being accommodated by her employer allowed her to transition back into a work-life balance that was appropriate for her. Moreover, most participants reported familial support as the most important and practical type support received:

“The other aspect is my wife is also my best friend so I had somebody I could talk to. Because a lot of people I was talking to that were there sometimes their relationship would get strange when one’s sick and one isn’t [...] But it was easy to do when you’re two doing it, you know?” (P10).

“First of all I would say my family, my spouse was always by me, during the post-treatment time. [...] If the family would not have been there, it would have been very, very difficult.” (P3)

“It has to be my family. As I said, my parents put their lives on hold to take care of me for those six months. I’m the oldest of two girls and my mom was like ‘oh, no, you need us, we’re here’ and the support has just been amazing with whatever decisions I’ve been taking and -- so that’s been good.” (P4)

Other participants reported receiving support from a group of friends: *“I have like four, five really really close friends and they were there. Like I could count on them” (P6).* A supportive social network undeniably plays an important role in the cancer survivor’s recovery. While the individual faces multiple challenges, a strong social network can diminish the negative impacts of cancer, acting as a sort of a buffer, by providing emotional

and psychological support. Unfortunately, not everyone has a well-established network they can rely on.

A person's attitude also acts as an influencing factor on the coaching intervention. The following statements suggest effective coaching outcomes and a positive survivorship journey are influenced by self-determination, initiative and positivity.

"I said 'did you read the book? Did you look into any of the books after?', 'No, I should've but I didn't'. You know what (name)? If you don't' read the books and apply the stuff, I wouldn't of gotten anything out of the course. I had to spend hundreds of hours in the library reading the book, re-reading, underlining, emphasising, making note, planning affirmations, basing my affirmations on what I saw in there and applying it to myself [...]" (P7).

"I think my attitude as well, I 've been very positive about everything that's happened. I was never 'why me, poor me' it was: 'well, why not me' [...] I never took the negative for me, it was always 'yeah ok, crap happens, you pick yourself up and you keep going' so I've been very positive about it all, I never took the negative." (P4).

In summary, each participant presents a set of unique characteristics that impacts the coaching process and its outcomes on survivorship. A supportive social network, a positive outlook and strong willingness appear to regulate how the experience will be perceived.

4.6 Barriers

Although there are many positive attributes to the Cancer Coaching Program, including various influencing factors, there are certain areas that were deemed not as helpful by cancer survivors. In keeping with the previous format, program and personal factors that impinge the Cancer Coaching experience are presented.

4.6.1 Program Barriers

Time and place of coaching sessions can cause inconveniences as the Cancer Coaching Program takes place at one location only – the Maplesoft Centre in Ottawa—and timing can be difficult to manage between the coach and client schedules: *"The only unfortunate thing about it, is that*

Ottawa is a big city, encompasses a lot of area geographically and it's not always easy in outlying rural parts of the city to necessarily get in to Maplesoft." (P5)

"But late sessions always have been very problematic for most of us living far from that place. [...] at that time I could not drive easily because my spouse had to take me there while she's working also because I was so weak and so forth but I have to rely – I don't know when she's free and things like that, yeah. [...] but the program is just they have already put the time there and you know, sometimes you have to skip it because sometimes it is not possible for you." (P3)

While later sessions accommodated some participants, they were problematic for others with different schedules. In addition, the location of the center acted as a barrier for individuals living far from the city center. Other program barriers included coordination of coaching sessions; including the way they are dispersed throughout the intervention, and the amount of coaching hours available: *"So you know, being able to have maybe ten hours with your cancer coach would be better? I don't know. But that's the only negative thing. We should unlimited use of them (laugh)."* (P6).

"When they first start the cancer coaching. Maybe the sessions should be a little closer together? Because I think all my sessions were equally spaced, like they were all—I don't know if there were three months apart of six weeks, I can't remember— But maybe at the beginning they should be a little more frequent—Because at the beginning you might have more concerns and things that you want to discuss". (P8)

Although the program prides itself in providing more coaching if needed, it is noteworthy that some participants were not aware of it. Perhaps this is a discrepancy in the way it is advertised by the program, or a lack of communication between the coach and the client. In addition to wanting more coaching hours, one participant recommended they be better coordinated, specifically at the stage where they are most needed. Conversely, requesting more hours – even wanting them to be unlimited-- suggests this is a helpful resource for cancer survivors and that perhaps in the future, hours can increase.

The cancer coach is for many, an important asset to the program and while the majority of participants raved about their coach's qualities, a few participants made recommendations for improvement. For instance, one participant described her coach as being too positive: *“Elle débordait toujours de positivisme et puis, tout était une bonne idée. Et puis j’avais l’impression que y’avait rien que je pouvais dire qui n’était pas brillant et puis en tout cas, j’ai trouvé—je l’ai trouvé trop positive.”* (P1). Additionally, one participant mentioned that a coach should be someone who has gone through a cancer diagnosis and is in the same age range as their clients:

“[...] but I feel you need somebody who’s been there? Done that. Not, not the coaching thing but the cancer process itself. To get an idea of how you feel. Because sometimes we don’t really know how we feel (laugh) it feel when somebody kind of, I guess, describes it at your place.”

“And maybe all we need is somebody—like different ages. Because you know, a youthful person for somebody young because they can relate to enjoying life and you know, they still have their life ahead of them so to speak. And you know it’s... that’s what I found.” (P2)

Another participant, who is in the palliative stage of cancer, discussed participating in a group session that was not proportionate in terms of gender and types of cancer. This created a situation where he could not relate:

“Maybe find out what happens, like I’m saying, they lump a lot of people together. I was in a group that I think I was the only one that had cancer. A lot of them were survivors that had it but didn’t have it anymore. So they needed support for good reasons, but you know? Or other people that were very stable. I think every group is different that’s the problem. If you get 10 women and one guy, the guy won’t get the same response as you go in as if there 10 guys and 1 woman. So that’s just luck of the draw I think. If I would recommend anything it’s probably to try and match people’s situations more accurately.” (P10).

Moreover, the extent of the coaching service and its scope of practice was described as unclear, and insufficiently explained by one participant, particularly at the start of the program. As a consequence, his needs surpassed the cancer coach's qualifications and were not addressed:

“I think it boils down to expectations. It took a month for her, that’s the coach, to decide that she wasn’t capable of helping me. She used the word qualified. So at that stage I began to think that my needs were more complicated for a regular cancer coach, so I suppose if my expectations were more clear at the beginning. What she could or could not do, and it might’ve helped her and myself. So I’m going back in my mind to thinking about my original talk with the original cancer people, and how they introduced the service and the scope of the service. I don’t remember, I can be wrong...but I can’t remember having discussed the limits and the scope of the types of coaching they could offer. [...]” (P11)

There are therefore aspects to the Cancer Coaching Program that can negatively affect a participant’s experience and ability to benefit, such as: the location and scheduling of coaching sessions, the sequence of sessions and their coordination, the quantity of coaching hours, coaches’ characteristics and incomplete information related to the scope of the coaching practice.

4.6.2 Personal Barriers

Personal barriers are circumstances that vary from one participant to the next; and they vary also in the degree to which they affect the experience. For instance, one participant described her living situation as disadvantageous:

“Yes because you know, especially when you’re living alone I find. Because again if, you know, if you’re into a partnership or whatever term you wanna use, you have somebody there to you know, more less bug you to come on, get with the program, start walking, do this, that and the other things. You know, but when you’re by yourself it’s out in the ocean.” (P2).

Others, described receiving little support from their social networks: *“I didn’t feel I was getting a whole lot of support from my family.” (P7).*

“[...] two younger daughters doesn’t call me, they doesn’t come over, they just quit everything and before they were here every day. And since I had my-- since I had the lymph nodes done, that was then I saw they, they stop coming. And when I had the double mastectomy, they keep out. Why I can’t say.” (P9)

4.7 Consequences

Every participant had different goals and issues they were coping with; each experienced the Cancer Coaching Program differently. As such, the participants experienced a variety of outcomes, which are portrayed in Table 3. The most significant outcomes of participating in the program were: 1) Acquiring the necessary tools and skill to manage the effects of the disease and a new post-cancer lifestyle, 2) networking with other cancer survivors, 3) attaining a more positive outlook, 4) gaining self-reliance, confidence and feeling empowered, 5) becoming more aware of personal assets and community resources, 6) to feel a sense of achievement and satisfaction and 7) feeling reassured and comforted.

Table 3: Main Outcomes Identified by Participants

Management of cancer impacts and new lifestyle	<i>“I’ve changed my nutrition, that was—taking some of the courses at the Maplesoft Centre. The Whole Foods course was amazing. Just being more aware of what I put into my body. Trying to get back into my fitness program.” (P4)</i> <i>“I feel strength which I didn’t feel because that time I was so weak, now I’m ok, I feel strength. My weight returned to the normal. My eating habit is ok [...] No I’m not still adjusting. I say that adjusted to this new normal.” (P3)</i> <i>“I’ve learned to live one day at a time. That’s probably the most important thing. And don’t sweat the small stuff.” (P10)</i>
Networking	<i>“[...] got to meet a lot of other women there who were sort of going through the same things that I was going through so that was a very positive thing...” (P8)</i> <i>“When I was doing the back to work program there was 12 other cancer survivors. In different stages, with different kinds of cancers, different totally--like completely different job experiences. So we shared tons of stuff amongst ourselves. What we were experiencing and you know, like, I hadn’t gone back to work yet. I was—I’m getting ready to go back to work but some of them had already you know, gone a couple weeks, or they were six months in, or they were a year in. So that was awesome. Like having the—being part of the program with all the other cancer survivors, that was, that was really good.” (P6)</i> <i>“[...] it was great because these people knew exactly what you were dealing with. They knew exactly.... Everything that I was feeling, they had felt. When we talked the 10 of us, we also went around the table and there was certain empathy for everybody there and we didn’t have to glorify. We just said this is what’s happening to me, and everybody understood. There was trust. That’s a big thing. There was certainly empathy that’s another big thing. There was respect, another good point. There was a common bond in that way. We’re all dealing with the same thing. Nobody had to hide it. Everyone was really open and never held anything back. [...] So, yeah that’s a critical part. Socialization. Socializing with people with common difficulties was therapeutic.” (P11)</i>
Positive impact on outlook	<i>“Oh no, I was pretty negative when I started here. If you were to read my reviews by (name of coach) she would’ve said that I’ve come a long way and the stress level’s way down. I was just very stressed when I started.” (P7)</i> <i>“[...] just realizing that people are not alone in this journey and maybe exposing me to other people so that I can share with so that, it’s taken me different offsprings, the Maplesoft Centre.” (P4)</i>

	<i>“Well, sort of, explaining to me to listen to my body and not my brain, if you want. And they do that you know, for some people they do yoga, some do, you know, different methods, you know? I’m not that sophisticated so, I’m more direct. You tell me ok, I’ll try to figure out that way, but there are different methods that they do tell you you can do to listen to yourself and accept the way it is. It was very useful that way.” (P10)</i>
Self-reliance, confidence, empowerment	<i>“The belief in myself and—yeah, belief in myself and, and there’s no right or wrong, everybody’s different but taking – being able to take charge of those decisions to give you that oomph, that belief in yourself that your able in taking charge [...] I’m taking control of my treatments or – these are my decisions, getting informed about different things and taking charge whereas before I wouldn’t be as forthright or as I wouldn’t say-- it’s not aggressive—assertive, that’s what I’m looking for. So becoming more assertive. These are the things that I’m looking for...” (P4)</i> <i>“Whereas before maybe I wouldn’t of been quite as assertive or saying ‘these are the things I’m looking for’ I would’ve just taken it or just followed along blindly, getting that information that it is about me, it’s my life, my choices, my decisions, getting the information required to make good choices, good decisions. But it all ends up being me so, owning that, helping me own that and have that power, it’s very... very empowering, that’s what I’m looking for, very empowering” (P4)</i> <i>“So I think that also helps me with the centeredness of everything. But yeah it had a really good positive impact from my attitude and my outlook and you know, I have more confidence. Asserting myself isn’t a problem anymore.” (P6)</i> <i>“[...] I think that like, she made me feel better and have a little more confidence and just feel more comfortable with, with my life the way it is now after cancer, as a cancer survivor.” (P7).</i>
Asset literacy	<i>“I guess the feeling that there are, you know there’s resources and people in the community that you can turn to when you’re dealing with major you know, I mean a major medical issue like cancer and that can help and can assist you-- I mean if you want, want their assistance or need it, it’s, it’s there.” (P5)</i> <i>“They were offering yoga at that time for people who had cancer—for women who had had cancer and, and were survivors and so, [...] I don’t know that I would’ve known about if I hadn’t gone to Maplesoft and you know, I think (name of coach) had told me about that “(P8)</i> <i>“[...] realizing that I really have a support system, and the Maple Soft offers some support to people [...]” (P10)</i>

Achievement & Satisfaction	<i>“Yeah but really I was happy because my objective was meant through the coaching system which I received through those programs. I was happy mmmm. Really happy.” (P3)</i> <i>“I felt better, to be honest with you, [...]. I feel better about it and what not when I see her and she supported me and said ‘you know, you’re doing the right things and you’ve come a’—and she looked at me and ‘you’ve come a long way (name) since you started, you know’ and she could see you know, how, how, the kind of impact this had had, on me and everything” (P7)</i> <i>“It’s a work in progress I mean (laughs) you have to do it yourself but certainly she gave me the tools to do it. So I was, I was, you know, I was quite happy with it as I had not had a good experience with the (name) Program and-- but this you know, worked very well for me.” (P5)</i>
Reassurance & Comfort	<i>“And we worked – well, we, we, she validated my fear of recurrence. And she made me feel like my fear was reasonable. She made me feel like my reaction to everything that happened to me was, was reasonable. And what I was going through was normal.” (P6)</i> <i>“I think the biggest help was that you know, she told me that this, this is the way that everyone feels you know, that everyone’s who’s had cancer feels that way and every time you, you are sick you know, right away your first thought is that you have cancer again and, and um, she reassured me that that was very, very normal to feel that way and that everyone feels that way” (P8)</i> <i>“Well it was good to feel that I hadn’t fallen off the radar. That they actually do care about you. You’re in this together, they’re at your support so she wants to touch base to see how things are going, do we need to tweak things, just seeing if I need something different, she would be there. If I need to go in or talk with her or, so that was very nice to know that I wasn’t just, not just a number. That they really do care about you and they want you to succeed, they want you to do well.” (P4)</i> <i>“I found it useful to find somebody to talk to and not feel guilty for not doing a lot or when I wasn’t connecting with people the way I would’ve liked to or the fact that I couldn’t do a lot of stuff. [...] I just accepted that as what I had to do to make myself well. It was just to take care of myself and rest and not feel guilty about what I couldn’t do you know? So that type of thing certainly helped.” (P12)</i>

While diverse outcomes were experienced, it is important to consider all influencing factors in order to have a full understanding of the outcomes lived by cancer survivors participating in the Cancer Coaching Program. As such, a Causal Paradigm Model for each participant illustrates the experience holistically; these are included in Appendix J.

4.8 Demographic Differences

Participants' individuality determined the course of the program as well as the outcomes. The third research question aimed to investigate this more in depth by exploring the variety in CCP experiences across demographics. The demographics collected, by means of a questionnaire collected at the recruitment stage, were: age, gender, type of cancer, employment status, living situation, total coaching sessions completed, cancer stage in which participation occurred, and starting and ending dates of participation (Table 2).

The sample had a mean age of 61.4 years; 42 years being the youngest and 71 years being the oldest. The main differences between the youngest and the oldest ages were related to differences in cancer impacts and coaching goals. For instance, the main effects of cancer for the youngest participant were impairments on sexual health and ability to work, and frustration related to diagnosis at a young age. Also, support networks mainly consisted of friends around a similar working age, which meant support was not available during the day. Main coaching goals for this participant included returning to work and receiving emotional support. In contrast, cancer impacts relevant to the oldest participant, were extreme fatigue and not being able to maintain hobbies, including socializing with friends. The main coaching goals for this participant were to obtain practical solutions to resume her hobbies.

Indeed, the effects of cancer were highly influenced by the person's age group, which is not surprising considering that each life stage varies in terms of roles, responsibilities and activities.

This factor determined the focus of the coaching sessions and its outcomes. Due to a rather small age-range however, with only one participant younger than 55 years old, further research with a larger variance in age groups is needed to investigate the role of age on the coaching process.

There did not appear to be any differences between female and male participants in terms of cancer side effects and coaching goals, apart from side effects related to specific cancer (i.e. breast cancer). Both genders had similar goals such as return to work, lifestyle changes and coping with physical and emotional issues; and both sought practical and emotional support from the program. This opposes the presumption that female participants would be more likely to seek emotional support. The females reported fear of recurrence more often, but there were fewer males in the sample, and two had either incurable or palliative cancer, for which fear of recurrence is not a factor.

Different types of cancer were also compared, but the analyses showed similar patterns in coaching experiences, and some differences within the same type of cancer. This reinforces the point that every cancer patient and their experiences have uniqueness.

Employment status was explored and differences in coaching experiences were found. Participants who were employed at the time of their participation in the program had common goals of returning back to work and finding work-life balance, as their abilities to work were impacted by the effects of cancer. For these participants, working represented the stability and normalness they had had before their cancer; it was for them a main priority during the coaching program.

Another demographic considered was participant living situations, which did influence the course of the CCP. Participants who lived alone did not have the same level of support as participants living with family members; this triggered their need for emotional support.

Participants living alone described the need to talk to someone and be motivated by another person. Conversely, participants who lived with a partner, children or both, described receiving a great amount of support from their families. Expectations from the coach thus differed according to whether participants lived alone.

The total number of coaching sessions completed were also explored however, it was difficult to conduct proper analyses as the data were inconsistent. Some participants described being able to get more coaching if they needed more, and they felt their needs were met with the total received. On the other hand, some participants mentioned more coaching sessions would have been preferred. In this particular group, some had had more sessions than in the other group. It was therefore difficult to describe the connection between the number of coaching sessions and coaching experiences.

Although this study aimed to explore the experiences of cancer survivors, three participants enrolled in the coaching program at the time of their diagnosis or during palliative treatment. Their inclusion in the analysis was advantageous, allowing for comparison of CCP experiences across different stages of cancer. Evidently, coaching goals were much different between participants in the survivorship phase and participants in the treatment phase. The latter sought coaching support mainly to cope with their current situations, including intense feelings related to fear and anxiety, while participants in the survivorship phase were action-focused, wanting pragmatic solutions to move on from their cancers. Regardless, the CCP program is designed to help individuals in all stages of cancer, including caregivers - and both groups were satisfied with their experiences.

4.9 Summary

In summary, this section presented cancer survivors' experiences with the CCP, including their various needs for support, the program's approach to addressing these, the influence of program and personal assets, as well as important consequences from participating in the program. It also highlighted the influence of demographic factors. As cancer survivors provided details on these aspects, it was possible to identify patterns and uncover the core phenomenon. This provided basis for grounded theory development. The next section provides details on this phenomenon, the emergent model, and the results in relation to the existing literature.

CHAPTER 5: DISCUSSION

The overarching purpose of this research was to explore the experiences of cancer survivors participating in a Cancer Coaching Program (CCP) developed by the Ottawa Regional Cancer Foundation (ORCF), and to explain the support it provides. As described in Chapter 1, the following three questions guided this research:

1. What types of issues are encountered by cancer survivors seeking support from the CCP?
2. How is the CCP helpful for cancer survivors?
3. How does the CCP experience vary across different demographics?

These questions were addressed in the results section (Chapter 4), presenting prevalent issues faced by cancer survivors and their needs for support, and the various ways these were addressed by the CCP. Also presented in the results section, were the influence of different demographic factors on the CCP experience. In this chapter, findings are discussed in relation to the survivorship and coaching literature. First, to guide the discussion, the core phenomenon of this study is presented.

5.1 Bridging the Gap

The core phenomenon captures the main theme in this research by conceptualizing in few words what the findings are about (Strauss & Corbin, 1990). As explained in section 3.4, the core phenomenon emerged after a rigorous process of coding. Each important category was developed and linked to another, with the help of a *causal paradigm model* (Strauss & Corbin, 1990). A model for each participant's experience was developed; and they were compared for similarities and differences.

Each participant lived unique experiences and discussed different outcomes; it was not clear at first what the common pattern was between them. Initially, the program was described as a compass for orientating cancer survivors towards their goals. It then was conceptualized as similar to a geographic positioning system (GPS), providing support to cancer survivors in step-by-step instructions. Because the program actively involves the individual, and requires participation and autonomy, a GPS seemed inappropriate to represent the roles of the survivor and the CCP. One thing remained clear however: cancer survivors began the program in a state of post-cancer dilemma with diverse needs and goals, and finished the program with their needs met and goals accomplished.

The program clearly acted as a catalyzing agent, providing the clients with the necessary supports, tools and skills to successfully accomplish their goals and meet their needs. The gap in survivorship care was apparent after identifying the various challenges cancer survivors face, and the types of support they required. In analyzing the various outcomes, the role of the CCP in bridging this discrepancy kept emerging as the dominant theme. Thus, the core phenomenon, as shown in Figure 3b, was identified as *bridging the gap*.

While Figure 3b provides a detailed representation of the coaching experience, Figure 4 specifically portrays ‘bridging the gap’ with finer granularity. In this figure, the CCP coloured boxes represent the program strategies and tools that are tailored to support individuals with a cancer experience. In collaboration, the cancer survivor and the coach utilize these strategies and tools to enable a successful passage from ‘point A’, a post-treatment state that is severely impacted by cancer, to ‘point B’, a post-coaching state where the cancer impacts are being managed and the survivor is integrating a ‘new normal’ lifestyle. The influences of personal and program factors, which act as facilitators or barriers, are acknowledged throughout the process.

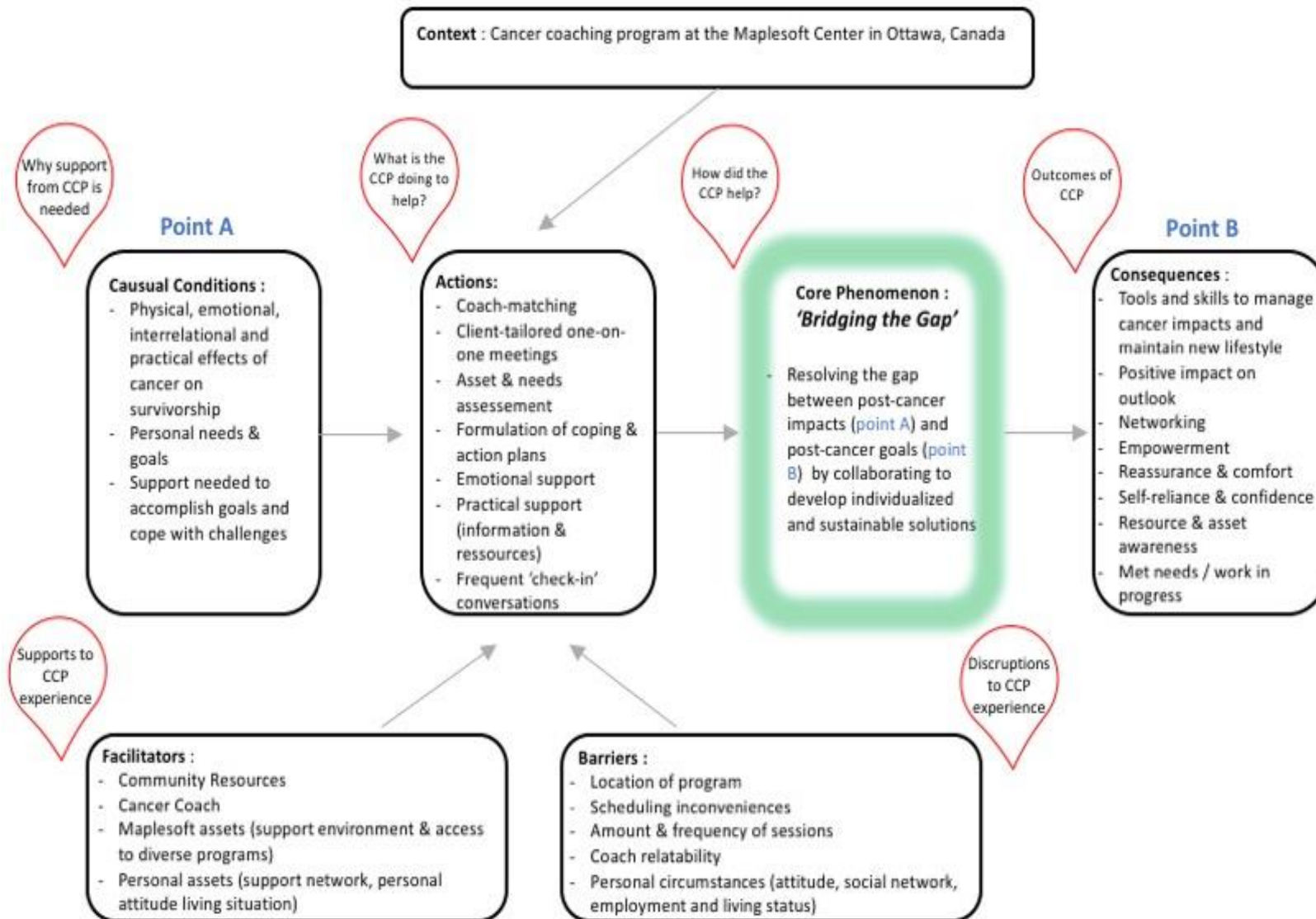


Figure 3b: An adapted *causal paradigm model* (Strauss & Corbin, 1990) highlighting the core phenomenon.

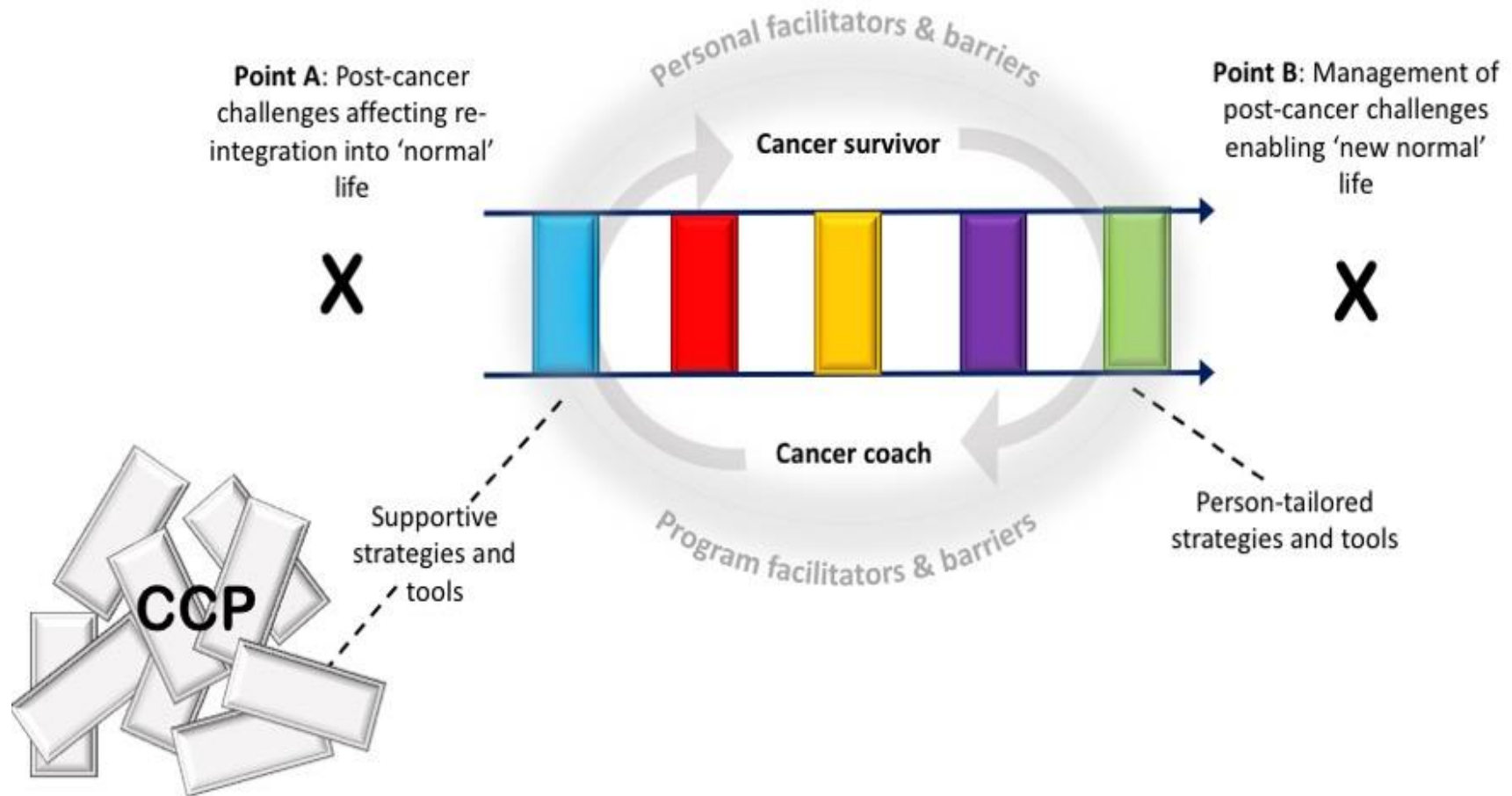


Figure 4: A detailed representation of 'bridging the gap'.

5.2 Needs for Support

The participants in this study were asked about the types of challenges they encountered, to understand what type of supports they were seeking when they initially registered for the Cancer Coaching Program. These challenges correspond to *causal conditions* (point A) in Figure 3b.

The participants' descriptions aligned with Jefford et al. (2008) and Jefford et al. (2012) who suggested the impacts of cancer are multi-dimensional, and survivors endure emotional, psychological practical and interpersonal effects. The most frequently reported psychological impact in the literature is fear of recurrence, which is prevalent between 33% and 96% of cancer survivors (Hewitt, Greenfield & Stovall, 2006; Jefford et al, 2008; Jefford et al., 2012; Simard et al., 2013; Ghazali et al., 2013; Koch et al., 2013). Indeed, 50% of participants in this study described feeling fearful their cancer would come back. It is important to note that this does not include two participants who were living with either palliative or incurable cancer.

The participants who did fear recurrence associated this fear with disconnection from the cancer system and having less frequent exposure to their doctors. Cancer survivors described being looked after so well and feeling reassured during the course of their treatment; but they felt alone and lost when they became survivors, triggering fear of recurrence. This finding aligns with Jefford et al. (2008) and Jefford et al. (2012) who related this fear to apprehension about leaving the security of the health care system and the periodic visits to health care professionals.

In this study, the participants described coping with persisting physical side effects such as extreme fatigue and memory loss. Some physical issues were specific to the type of cancer, such as hormonal and prosthetic issues for survivors of breast cancer. In fact, these effects, particularly fatigue and hormonal issues, were mentioned to cause strain on personal relationships; a finding which is supported in the literature (Zebrack & Isaacson, 2012; Roland et

al., 2013; Stanton, 2012; Jefford et al., 2008; Schmitt et al., 2008; Oktay et al., 2011). Other social issues described by participants in this study included having difficulties talking about their cancer experiences at work or with friends, and doing things to avoid making others uncomfortable. Many participants reported experiencing minimal compassion. These results are consistent with the literature, which suggests that relating to others after having cancer is a challenge (Jefford et al., 2012).

The literature also suggests that practical issues such as re-integrating into the workplace and financial hardship are typical (Mehnert & Kock, 2013; Zebrack & Isaacson, 2012; Jefford et al., 2012). As participants in this study described the challenges of re-integrating into their 'normal' lives, work-related issues were the most frequently reported, which included loss of employment, early retirement, work accommodation, and expressing concerns with employers.

Based on these findings, it is clear that the effects of cancer persist into the survivorship stage, and that transition into this stage is impaired by a general lack of guidance and support. These challenges represent important needs for support in the survivor population and confirm the gap that exists in survivorship care.

5.3 A Person-Tailored Approach

To support the various and unique needs of cancer survivors, the CCP adopts a person-tailored approach. This allows for the use of different strategies and techniques across participants with different needs. Actually, a flexible design is characteristic of coaching interventions and allows for provision of appropriate and personalized care that addresses the specific needs of the client (Olsen, 2014).

Person-tailored support was achieved through an amiable and trusting partnership between the cancer coach and the participant, which facilitated the process of identifying valued goals and

establishing a plan to achieve them. In developing action strategies based on participant's personal assets, the coaches embodied an approach that, based on the literature, fosters progress towards personal goals (Wagland et al., 2014). Based on the findings of this study, the CCP's approach to providing person-centered support did in fact benefit goal achievement.

Furthermore, the literature identifies collaboration as a main attribute of health coaching, which facilitates person-centeredness (Olsen, 2014). In concurrence, these findings illustrate the positive influence of a coach-client partnership on participants' overall experiences with the program.

To further ensure a person-centered approach, the CCP developed a coach-matching process that pairs participant needs with coaches' experiences. This technique was shown to be effective as participants expressed satisfaction with their coach's ability to meet their needs. Whether this concurs with existing knowledge is unknown, as no other studies using coach-matching were found.

As cancer affects individuals on physical, psychological, emotional and social factors, it is imperative they be cared for in a holistic manner (Lovell, 2014). The cancer coaching approach was summarized as nurturing, with more support available if needed, and customizable to help different people with different needs. Based on participants' descriptions, the cancer coaching approach is not a "cookie-cutter" one.

5.4 Facilitators and Barriers to Coaching Experience

To fully capture cancer survivors' experiences with the CCP, it was important to identify influencing factors. Community resources, program features and the participant's assets were identified either as facilitators or barriers that influenced the course of the program and its outcomes.

Community resources were identified as local groups and specialized services such as physiotherapy and psychotherapy. Due to the limits of the coaching scope of practice, these available resources helped the cancer coaches complete their task of providing support to individuals in need of intensive services. In fact, one participant alluded to this as he described his profound psychological needs surpassing the expertise of the cancer coach and being referred to a more appropriate service. This is consistent with observations by Moore and Jackson (2014) and Bird and Wanner (2015) that coaches provide expert knowledge when it is appropriate, in areas in which they have obtained professional accreditation— otherwise they refer clients to experts who are better suited for the task. The main role of the coach is not a psychologist for example, but rather to encourage individuals to move forward with their goals, to guide and support them (Bird & Wanner, 2015)

Consequently, this created confusion among the participants regarding the extent of the coaching practice. Coaching is widely used as an intervention strategy across various disciplines, and is recognized for lacking conceptual clarity; therefore this was not a surprising finding (Olsen, 2014). In this study, referrals to community resources enabled coaches to successfully help their clients navigate, as well as to promote resource awareness and self-efficacy in cancer survivors.

Facilitating factors also stemmed from the program itself. Attributes of the Maplesoft environment and the cancer coaches were emphasized in participants' recounts of their experiences with the CCP. More specifically, participants described the Maplesoft environment as warm, supportive, welcoming, safe, and unlike typical health care settings; they felt comfortable exposing their vulnerabilities and sharing them with others. Participants described feeling at home there, and associated the center with healing.

Additionally, this multidisciplinary environment prides itself in providing all sorts of programs and workshops, which evidently complimented the coaching experience. Participants appreciated the availability of diverse services and felt the centre was well designed to address most needs and to provide various types of support. After a review of the literature, no coaching intervention was found that delivered this type of service in such an environment. In fact, most occurred over the telephone or in clinical practice (Wolever, Caldwell, Wakefield, Little, Gresko, Shaw, Duda, Kosey & Gaudet, 2011; Lynch, Brigid, Courneya, Sethi, Patrao, & Hawkes, 2014; Thom, Ghorob, Hessler, De Vore, Chen & Bodenheimer, 2013; Yang, Wroth, Parham, Strait & Simmons, 2013; Thom, Willard-Grace, Hessler, DeVore, Prado, Bodenheimer & Chen, 2015; Karhula, Vuorinen, Rääpysjärvi, Pakanen, Itkonen, Tepponen, Junno, Jokinen, van Gils, Lähteenmäki, & Kohtamäki, 2015).

Moreover, the cancer coaches were described as significant assets to the CCP and many participants spoke positively about their coaches. Specific character traits and skills acknowledged were openness, good listening skills, authenticity, competence, accessibility, reassurance, comfort, positivity, reliability and helpfulness. Participants described these characteristics as the main reasons their coaching experience was positive. This finding indicates that satisfaction with the CCP was heavily influenced by whether the coach possessed these traits. It is unknown if these findings are consistent with existing literature as there is scant qualitative research on participants' coaching experiences.

Also identified in participants' narratives were the importance of available support to family members, who also endure the effects of cancer. Coaching was depicted as a highly beneficial support for caregivers, which in turn, had positive effects on participants. This finding concurs with existing studies that reveal the importance of including caregivers in the coaching process

(Hibbs, Magill, Goddard, Rhind, Raenker, Macdonald, Todd, Arcelus, Morgan, Beecham & Schmidt, 2015).

Furthermore, personal circumstances were studied to understand their degree of influence on the CCP experience. The presence of a support network, which was mainly described to consist of family members, was a significant influencer. In fact, Forsythe, Alfano, Kent, Weaver, Bellizzi, Arora, Aziz, Keel and Rowland (2014) state that social support, particularly from a spouse, facilitates self-efficacy of cancer survivors in decision-making and participation in follow-up cancer care. In addition, a positive and determined outlook also had a strong influence on coaching outcomes, which Ranking (2013) explains is associated with better self-care, healthier choices and healing in patients. These were valuable findings, as when these factors were absent, participants tended to report less favorable experiences.

How cancer survivors experience and perceive the CCP, and how beneficial the outcomes will be, is heavily influenced by community, program and personal factors. These factors – and whether they act as facilitators or barriers – vary from one participant to another; this finding supports the recommendation for using a person-tailored approach.

5.5 Consequences of Cancer Coaching

Outcomes of cancer survivors' participation in the CCP were diverse. This stems from the uniqueness of each participant in cancer diagnosis, treatment pathways, side-effects experienced, and personal circumstances. In participating in the CCP, cancer survivors acquired the necessary tools and skills to manage the effects of the disease and maintain new lifestyles. Survivors felt empowered, more self-reliant and confident. These outcomes are similar to other studies (Lanese et al., 2011; Kivelä, Elo, Kyngäs, & Kääriäinen, 2014; Wagland et al., 2014).

Furthermore, due to Maplesoft's multidisciplinary, social and caring environment, participants also had opportunities to network with other cancer survivors, which made them feel confident, secure and understood. Other studies (Stelter, Nielsen, & Wikman, 2011) have shown similar effects of coaching, but with young athletes. Scarce literature was found on coaching interventions in environments such as the Maplesoft Centre.

In addition, participants completed the CCP with a sense of accomplishment and satisfaction, which was consistent with findings reported by Wagland et al. (2014). Participants gained a more positive outlook and became more aware of their personal assets and community resources.

In summary, the findings from this study provide useful insights into cancer survivor experiences with the CCP, as well as the factors involved in making that experience beneficial. The outcomes of participating in the CCP were diverse; determined by factors such as individual needs and goals at the start of the program; community, program and personal factors and individual demographics. These outcomes were important, for finding the new 'normal' after cancer.

The findings of this study confirm that the challenges of cancer are profuse and persist into the survivorship stage. A support service such as the Cancer Coaching Program is a promising approach to bridging this gap. It is thus important that consideration be given to this program and coaching in general, to facilitate the recovery of individuals having gone through cancer. The number of cancer survivors is rapidly increasing and is of outmost importance that these individuals receive the appropriate support to re-integrate back into daily life.

5.6 Limitations of the Study

This study has limitations that should be acknowledged. First, sample demographics were not equally proportionate in terms of cancer type and sex. Most participants (n=8) identified as female, compared to (n=4) males. Nearly 60% of the sample were survivors of breast cancer,

which is not surprising considering the sample consisted mainly of females and breast cancer is a predominant type of cancer in women. A larger sample could allow a better representation of cancer types and gender. Second, Table 1 demonstrates that CCP clients are primarily older female breast cancer survivor. It is possible that this type of program attracts a certain portion of the total cancer survivor population and that the representation of these findings are limited to the program's most frequent users, which are women between 55 and 64 years who are survivors of breast cancer. Third, the CCP takes place at one location: the Ottawa Regional Cancer Foundation. The reach of this program is potentially limited to its urban location, causing participants from rural areas or at far distance from the centre, not to register. Fourth, specific criteria for participant inclusion were established by the author for feasibility purposes. It is therefore possible that this study's findings are limited by the criteria established to define "cancer survivors", potentially excluding different groups of cancer survivors. Finally, it was difficult to evaluate whether the total number of coaching sessions had an effect on cancer survivors' experience with the program, as the number of sessions varied across the sample.

CHAPTER 6: CONCLUSION

The present chapter summarizes the contributions of this research to the field of survivorship care and health coaching, and its implications for practice. Future research opportunities are also presented.

6.1 Contribution to Knowledge

There is a known discrepancy in psychosocial support and follow-up cancer care for cancer survivors, to address the multi-dimensional and long-lasting effects of the disease. Health and life coaching interventions have been shown to have beneficial outcomes on survivor recoveries and are promising for the provision of survivorship care. While experimental studies have used quantitative metrics to measure the outcomes of coaching, this research was based on cancer survivors' lived experiences. Using a grounded theory approach, the study was the first to explore the effects of the Cancer Coaching Program developed by the Ottawa Regional Cancer Foundation, from which positive effects on psychosocial variables were found. This project provides a grounded theory on the role of the program, in bridging the gap to survivorship.

In participating in the Cancer Coaching Program, cancer survivors acquired the necessary tools and skills to manage the effects of the disease, adapt their lifestyles and achieving their personal goals. They also had opportunities to network with other cancer survivors. After participating in this program, survivors had more positive outlooks on life, and reported confidence and a sense of empowerment. This study provides evidence that a cancer-specific coaching design has beneficial outcomes for cancer survivors, by bridging the gap between their needs and desired goals.

6.2 Implications for Practice

This study contributes a grounded theory that describes the role of the Cancer Coaching Program in bridging the gap to a healthy recovery after having had cancer. Specifically, this research provides detailed insights into cancer survivor's coaching experiences, including various psychosocial outcomes that emerged. This theory can provide guidance for the improvement of follow-up cancer care, including the development of support programs and psychosocial health initiatives. The findings identify key components to survivorship care to support a healthy physical, emotional, mental and social quality of life after cancer.

6.3 Future Research

This thesis project explored the lived experiences of cancer survivors who participated in a Cancer Coaching Program. Moving forward, it would be valuable to test the “bridging the gap” concept by applying the grounded theory in a larger, diverse population of cancer survivors. The impacts of the CCP could be explored in other cancer populations, such as with patients in the diagnostic/treatment phases and caregivers. In fact, the program offers coaching to these populations, providing a platform for future research projects.

Additional studies are also needed to quantify the impacts of these outcomes and evaluate their importance on the lives of cancer survivors. An experimental study would be beneficial for testing pre and post-test effects on psychosocial variables. Finally, future studies could evaluate the impacts of the program, out of the Maplesoft context and in different settings, to determine more fully the role of the contextual factors.

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APPENDICES

Appendix A: Initial Consultation Form *(Permission to use this document provided by the Ottawa Regional Cancer Foundation)*

Cancer Coaching Initial Consultation Record

Cancer Coach:		Date:	
Client name:		DOB	
Client is a: ☐ Cancer Survivor ☐ Caregiver		(For caregiver, include relationship to the cancer survivor if applicable)	
Date of initial diagnosis:			
Diagnosis:			
Current stage in the cancer journey: ☐ Newly Diagnosed ☐ In Treatment ☐ Post Treatment			
☐ Metastatic/Recurrence ☐ Palliative			
Distress Rating: ☐ No stress ☐ Mild stress ☐ Medium Stress ☐ High Stress (Insert the level of stress if applicable to your consultation)			
Quality of Life Rating: ☐ Excellent ☐ Very Good ☐ Good ☐ Fair ☐ Poor (insert QOL rating if applicable to your consultation)			
Above the Decision Line			
Client health needs:		Health Needs Categories: tick all that apply, circle 1st priority	
		☐ Information about the disease and/or treatment choices ☐ Manage side effects ☐ Manage post treatment transitions ☐ Manage return to work/work issues ☐ Decrease smoking ☐ Decrease alcohol use ☐ Increase physical activity ☐ Improve nutrition ☐ Manage weight change ☐ Know about/ connect to resources ☐ Sexuality/intimacy/fertility ☐ Memory/concentration ☐ Fatigue/sleep/energy ☐ Stress/mood/emotions/isolation ☐ Finances/legal ☐ Spirituality/faith/meaning/purpose of life ☐ Caregiver support ☐ Children/Youth Coping with Cancer in the family ☐ Grief and bereavement ☐ Manage practical issues ☐ Deal with changes in appearances ☐ Manage pain ☐ Better manage social/family relationships ☐ Others (please specify)	
Other client issues:			
What is the client currently doing to improve their health and well-being:			
Initial RICK to work on lifestyle/treatment category:		Subsequent RICK: (if decisional balance used)	
R	Low Medium High <u>or</u> /10	R	Low Medium High <u>or</u> /10
I	Low Medium High <u>or</u> /10	I	Low Medium High <u>or</u> /10
C	Low Medium High <u>or</u> /10	C	Low Medium High <u>or</u> /10
k	Low Medium High	k	Low Medium High

Provided decisional balance assistance? Yes ☐ No ☐ Decision made to work on chosen issue? Yes ☐ No ☐	Intrinsic motivator/s _____ _____ _____ _____			
Below the Decision Line				
Options for working on chosen category:				
Personal goal/s: (specifically what behaviour, how much, how often, start and review timeframes, realistic?). Write goal/s below, OR use the ICAN Plan to document each goal and plan. 1. _____ 2. _____ Pre-measure: quantify the patient's current behaviour for each personal goal: 1. _____ 2. _____				
Action Planning				
Barriers to change: ☐ Behaviours ☐ Emotions ☐ Situations ☐ Thinking	Items to include in action plan: (attach copy of planned actions) <table border="1" style="width: 100%; border-collapse: collapse; margin-top: 5px;"> <tr> <td style="width: 25%; padding: 5px; vertical-align: top;"> ☐ All micro steps needed ☐ Cues to remember steps ☐ Support people ☐ Other support </td> <td style="width: 25%; padding: 5px; vertical-align: top;"> ☐ ANNTs into PETs ☐ PETs practice ☐ Contingency plan/s ☐ Relapse prevention </td> <td style="width: 50%; padding: 5px; vertical-align: top;"> ☐ Emotion management ☐ Review/referral ☐ Rate Importance /10 ☐ Rate Confidence /10 </td> </tr> </table>	☐ All micro steps needed ☐ Cues to remember steps ☐ Support people ☐ Other support	☐ ANNTs into PETs ☐ PETs practice ☐ Contingency plan/s ☐ Relapse prevention	☐ Emotion management ☐ Review/referral ☐ Rate Importance /10 ☐ Rate Confidence /10
☐ All micro steps needed ☐ Cues to remember steps ☐ Support people ☐ Other support	☐ ANNTs into PETs ☐ PETs practice ☐ Contingency plan/s ☐ Relapse prevention	☐ Emotion management ☐ Review/referral ☐ Rate Importance /10 ☐ Rate Confidence /10		
Referrals to programs at the Maplesoft Centre and/or in the community				
Type of program of interest to the client ☐ Wellness programs (weekly, workshops/seminars, comprehensive) ☐ Healing Therapies ☐ 1:1 Cancer Coaching ☐ Group Coaching Programs of interest:	Referrals to community resources: Handouts provided:			
Notes:				
Signature:				

Appendix B: I Can Plan *(Permission to use this document provided by the Ottawa Regional Cancer Foundation)*

My ICAN Plan

Client Name:	DOB:
My Personal Goal: Write one or two sentences: What is important to you? What do you want to achieve? 	
Action Plan: Write down the things that you will need to do to achieve your personal goal. Fill in only as many lines as you need. Tick when achieved.	
☐	
☐	
☐	
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☐	
☐	
☐	
☐	
☐	
How much do you want to achieve this health goal? (Circle the number that applies) (Not at all) 1 2 3 4 5 6 7 8 9 10 (Very much)	
How confident are you that you will achieve this health goal? (Circle the number that applies) (Not at all confident) 1 2 3 4 5 6 7 8 9 10 (Very confident)	
What do you need to be thinking of, to maximize your chances of success? 	

Who or what else can support your efforts?	
What have you done in the past that helped you overcome obstacles?	
Date of my follow-up meeting:	Cancer Coach:

Appendix C: Check-In Form *(Permission to use this document provided by the Ottawa Regional Cancer Foundation)*

Cancer Coaching “Check-in” Consultation Record

Cancer Coach:	Date:
Date of registration confirmation:	
Check-in conversation: ☐ 3 months ☐ 6 months ☐ 9 months ☐ 12 months ☐ Other (indicate)	
Client name:	DOB:
Client is a: ☐ Cancer Survivor ☐ Caregiver	(For caregiver, include relationship to the cancer survivor if applicable)
Date of initial diagnosis:	
Diagnosis:	
Current stage in the cancer journey: ☐ Newly Diagnosed ☐ In Treatment ☐ Post Treatment	
☐ Metastatic/Recurrence ☐ Palliative	
Self-Assessment	
Considering your overall level of concern, how do you rate the level of stress you have been experiencing in the past week, including today? ☐ Significantly Worse ☐ Slightly Worse ☐ Same as Before ☐ Some Improvement ☐ Significant Improvement	
Compared to when you first registered with us, how do you rate your overall sense of empowerment -- your ability to take an active role in your own health and well-being outside the Centre? ☐ Significantly Worse ☐ Slightly Worse ☐ Same as Before ☐ Some Improvement ☐ Significant Improvement	
Compared to 3 months ago, and NOW how do you rate your overall quality of life? ☐ Significantly Worse ☐ Slightly Worse ☐ Same as Before ☐ Some Improvement ☐ Significant Improvement	
Are there other health needs that you would like to focus on at this time, through Cancer Coaching? (tick all that apply)	
☐ Information about the disease and/or treatment choices ☐ Manage side effects ☐ Manage Post Treatment Transitions ☐ Manage return to work/work issues ☐ Decrease smoking ☐ Decrease alcohol use ☐ Increase physical activity ☐ Improve nutrition	☐ Fatigue/Sleep/Energy ☐ Stress/mood/emotions ☐ Finances/Legal ☐ Spirituality/Religion/Meaning ☐ Caregiver Support ☐ Children/Youth Coping with Cancer in the family ☐ Grief and Bereavement ☐ Manage Practical Issues

☐ Manage Weight Change ☐ Connect to resources ☐ Sexuality/intimacy/fertility	☐ Deal with Body Image ☐ Pain ☐ Other (provide details)
Personal goal/s: (specifically what behaviour, how much, how often, start and review timeframes, realistic?). Write goal/s below, OR use the ICAN Plan to document each goal and plan. 1. 2. Goal 1: ☐ Rate Importance /10 ☐ Rate Confidence /10 Goal 2: ☐ Rate Importance /10 ☐ Rate Confidence /10	
Action Planning and Next Steps	
☐ Client Needs have been met ☐ Client Needs have not been met -- Revised health goals and action plan ☐ Client Needs have not been met -- Client is not interested/able to participate at this time ☐ Client has identified new health need – New health goals and action plan	
For clients who are continuing with Cancer Coaching	For clients whose needs have been met
Type of program of interest to the client ☐ Wellness programs (weekly, workshops/seminars, comprehensive) ☐ Healing Therapies ☐ 1:1 Cancer Coaching ☐ Group Coaching Programs of interest: Additional referrals to community resources: Additional handouts:	Ongoing involvement with the Foundation: ☐ Becoming a volunteer ☐ Organizing or participating in a fundraising event ☐ Make a donation ☐ Sharing their story/providing a testimonial
Notes: 	
Signature:	

Appendix D: Goal Review Consultation Form *(Permission to use this document provided by the Ottawa Regional Cancer Foundation)*

Goal Review Consultation Record

Cancer Coach	Date:
Client name: DOB: Distress Rating: ☐ No stress ☐ Mild stress ☐ Medium Stress ☐ High Stress (Insert distress rating if applicable to your consultation) Quality of Life Rating: ☐ Excellent ☐ Very Good ☐ Good ☐ Fair ☐ Poor (insert QOL rating if applicable to your consultation)	
Progress Review and Goal Setting this Consultation	
Current success and barriers: personal goal 1 Goal attainment personal goal 1: Not Attempted - Abandoned - Taking Action - Other __ - Quantify behaviour change: 	Current success and barriers: personal goal 2 Goal attainment personal goal 2: Not Attempted - Abandoned - Taking Action - Other __ - Quantify behaviour change:
Continuing/modifying current action plan: Yes/No Presenting issues this consultation: 	Tip: if modifying previous goal and/or action plan, check I & C of RICK Tip: new lifestyle/treatment category → use new Cancer Coaching Consultation Record
Spontaneous Change	
List any other healthy changes made that were not planned in previous consultations:: 	

Action Planning					
Barriers to change:	Items to include in action plan: (attach copy of planned actions or ICAN Plan))				
☐ Behaviours ☐ Emotions ☐ Situations ☐ Thinking	☐ All micro steps needed ☐ Cues to remember steps ☐ Support people ☐ Other support	☐ ANNTs into PETs ☐ PETs practice ☐ Contingency plan/s ☐ Relapse prevention	☐ Emotion management ☐ Review/referral ☐ Rate Importance /10 ☐ Rate Confidence /10		
Notes _____ _____ _____ _____ _____ _____ _____ _____ _____ _____ _____					
Signature: _____					

Appendix E: Ethics Certificate

This ethics certificate was granted on August 28, 2014 by the University of Ottawa's Research Ethics Board for the "Bridging the Gap – A Grounded Theory of Cancer Coaching Experiences" project, and renewed on August 28, 2015.

File Number: H04-14-01

Date (mm/dd/yyyy): 11/19/2015



Université d'Ottawa
Bureau d'éthique et d'intégrité de la recherche

University of Ottawa
Office of Research Ethics and Integrity

Ethics Approval Notice Health Sciences and Science REB

Principal Investigator / Supervisor / Co-investigator(s) / Student(s)

<u>First Name</u>	<u>Last Name</u>	<u>Affiliation</u>	<u>Role</u>
Tracey	O'Sullivan	Health Sciences / Others	Supervisor
Sarah-Nicole	Simard	Health Sciences / Others	Student Researcher

File Number: H04-14-01

Type of Project: Master's Thesis

Title: Bridging the Gap - A Grounded Theory of Cancer Coaching Experiences

Renewal Date (mm/dd/yyyy)	Expiry Date (mm/dd/yyyy)	Approval Type
08/28/2015	08/27/2016	Ia

(Ia: Approval, Ib: Approval for initial stage only)

Special Conditions / Comments:
N/A

Appendix F: Recruitment Notice (English)



uOttawa

Université d'Ottawa

Faculté des sciences de la santé

École interdisciplinaire des
sciences de la santé

University of Ottawa

Faculty of Health Sciences

Interdisciplinary School of Health
Sciences

A Psychosocial Impact Analysis of a Cancer Coaching Program

Dear potential participant,

I am writing to let you know about an opportunity to participate in a research study about the impact of a Cancer Coaching program on adult cancer survivors as well as on caregivers. This study is being conducted by Sarah-Nicole Simard, a graduate student under the supervision of Dr. Tracey O'Sullivan at the University of Ottawa, to inquire about your experiences of being a participant in the Cancer Coaching Program implemented by the Ottawa Regional Cancer Foundation.

If you choose to participate, your participation will consist of one 45-minute interview conducted either at the Ottawa Regional Cancer Foundation or by telephone. You will be asked to reflect on your experience as a participant in a Cancer Coaching Program and to provide recommendations for improvement. Additionally, you will be asked some questions related to your experience with the current health system.

If you are interested in participating in this study or if you would like additional information, please contact Sarah-Nicole Simard. Participants will be recruited on a first come-first served basis.

Please note that agreement to be contacted or a request for more information does not obligate you to participate in any study. Furthermore, if you express interest to participate, it does not mean that you are automatically enrolled for the study.

Thank you for considering this research opportunity!

Sarah-Nicole Simard

Faculty of Health Sciences,
University of Ottawa
25 University Pk., Ottawa, ON,
K1N 6N5
Email: hss-adj@uOttawa.ca

Appendix F: Recruitment Notice (French)



uOttawa

Université d'Ottawa

Faculté des sciences de la santé

École interdisciplinaire des
sciences de la santé

University of Ottawa

Faculty of Health Sciences

Interdisciplinary School of
Health Sciences

Une analyse de l'impact psychosocial du programme *Cancer Coaching*

Cher(ère) participant(e) potentiel(le),

Je vous contacte afin de vous informer qu'il vous est possible de participer à un projet de recherche qui évaluera l'impact du programme *Cancer Coaching* dans la vie des survivants du cancer et des aidants naturels. Cette étude est dirigée par Sarah-Nicole Simard, une étudiante à la Maîtrise sous la supervision du Dr. Tracey O'Sullivan à l'Université d'Ottawa et elle vise à compiler des informations sur votre expérience avec le programme *Cancer Coaching*, développé par la Fondation du Cancer de la région d'Ottawa.

Si vous désirez participer, vous serez invités à participer à une entrevue de 45 minute qui aura lieu soit à la Fondation du Cancer d'Ottawa ou par téléphone. On vous posera des questions en lien avec votre expérience comme participant dans le programme *Cancer Coaching* en plus de faire des suggestions des recommandations. De plus, on vous demandera des questions concernant le système de santé actuel et vos expériences avec celui-ci.

Si cette étude vous intéresse, ou bien que vous désiriez d'amples informations, veuillez contacter Sarah-Nicole Simard. Les participants seront acceptés selon le principe « premier arrivé, premier servi ».

Veuillez noter que si vous désirez être contacté ou que vous demandiez plus d'information, cela ne vous oblige à rien, vous n'êtes pas obligé de participer. De plus, si vous exprimez un intérêt particulier à cette étude, vous n'y êtes pas automatiquement inscrits.

Merci de votre intérêt, j'espère entendre de vous sous peu!

Sarah-Nicole Simard

Faculty of Health Sciences,
University of Ottawa
25 University Pk., Ottawa, ON,
K1N 6N5
Email: hss-adj@uOttawa.ca

Appendix G: ORCF Introduction Letter (English & French)



Dear clients,

We are pleased to introduce a very interesting research project we are supporting, conducted by Sarah-Nicole Simard, a Master's student at the University of Ottawa.

As you may know, the Ottawa Regional Cancer Foundation is the first in Canada to offer cancer coaching. To further develop and refine the program, it is instrumental for us to provide evidence related to its impacts on cancer patients. An independent assessment of our Coaching Program would therefore help us understand which aspects of the program are beneficial and what we can improve. Sarah-Nicole's research will serve as an analytical tool to measure the psychosocial impact of the Cancer Coaching Program on people facing cancer.

If you are interested, you will find detailed information in the recruitment letter as well as the consent form which is included in the envelope.

We would also like to emphasize that your participation in this research project will not affect the services you are receiving.

We thank you for considering this opportunity.

Cher(e)s client(e)s,

Nous avons le plaisir de vous présenter un projet très intéressant que l'on appui, mené par Sarah-Nicole Simard, une étudiante à la maîtrise à l'Université d'Ottawa.

Comme vous le savez peut-être, la Fondation du cancer de la région d'Ottawa est la première au Canada à offrir un service de coaching en matière de cancer. Afin de développer davantage le programme, il est essentiel que nous puissions quantifier et démontrer les résultats quant à l'impact sur les personnes atteintes du cancer. Cela étant dit, une évaluation indépendante du programme de coaching en matière de cancer nous aidera à cibler les aspects bénéfiques du programme et ceux en besoin d'amélioration. Le projet de recherche mené par Sarah-Nicole analysera l'impact psychosocial des personnes atteintes du cancer qui participent au programme de coaching en matière de cancer.

Si cette étude vous intéresse, vous retrouverez tous les détails dans la lettre de recrutement et de consentement qui sont toutes les deux incluses dans cette enveloppe.

Nous aimerions également souligner que votre participation à cette recherche n'affectera aucunement les services que vous recevez.

En vous remerciant de votre intérêt pour cet appel de candidatures.

Linda Eagen
President and CEO o Présidente et chef de la direction

Appendix H: Consent Form (English)



Université d'Ottawa

Faculté des sciences de la santé

École interdisciplinaire des
sciences de la santé

University of Ottawa

Faculty of Health Sciences

Interdisciplinary School of Health
Sciences

Faculty of Health Sciences,
University of Ottawa
25 University Pwt., Ottawa, ON,
K1N 6N5
Email: hss-adj@uOttawa.ca

A Psychosocial Impact Analysis of a Cancer Coaching Program

Primary Investigator:

Sarah-Nicole Simard

Thesis Supervisor:

Dr. Tracey O'Sullivan

Purpose of the Study: The purpose of the study is to explore the impact of the Cancer Coaching Program (CCP) implemented by the Ottawa Regional Cancer Foundation on cancer survivors as well as caregivers.

Participation: My participation will consist of one, 45-minute interview, conducted either at the Ottawa Regional Cancer Foundation or by telephone. I will be asked to reflect on my experience as a participant in a CCP and provide recommendations for improvement. I will also be asked some questions related to my experience with the current health system. Additionally, I will be asked to provide some demographic information, such as my age, occupation and living arrangements and to provide details on my cancer diagnosis and treatment period.

Risks: My participation in this study will be limited to discussing my experience as a participant in the Cancer Coaching Program. I understand that discussing these experiences may cause me emotional or psychological distress. I have received from the researcher assurance that every effort will be made to minimize these risks and that should I feel uncomfortable, I may refuse to answer any questions asked by the researcher or, stop the interview at any time. Before the start of the interview, I will receive information on the Ottawa Hospital Psychosocial Oncology Program at the Cancer Centre, should I ever feel the need to consult a psychologist.

Benefits: My participation in this study will provide insight on patient experiences during a Cancer Coaching Program. The positive as well as negative outcomes highlighted from the experiences will reflect the feasibility and appropriateness of the intervention in relation to the context of young adults dealing with cancer. This study seeks to provide a model that describes the psychosocial impact such a program can have on patients. This may lead to the development of research and future initiatives aiming to provide Cancer Coaching Programs to all cancer patients.

Confidentiality and anonymity: I have received assurance from the

researcher that the information I share will remain strictly confidential. I understand that my confidentiality and anonymity will be protected through the removal of my name from all stored recordings and documents. No names will be used in the study and any quotations used in the research reports will have removed all identifying information.

Conservation of data: All paper data will be kept in a locked cabinet at the University of Ottawa in the research lab of Dr. Tracey O’Sullivan. Electronic data files will be password-protected and only researchers directly involved in the study will have access. Upon completion of the study, information gathered will be stored for 10 years. Data conservation will end June 2024. After this time, all electronic materials will be permanently deleted and all paper materials will be destroyed. The list of participant names and contact information will also be discarded at this time.

Voluntary Participation: I am under no obligation to participate and if I choose to participate, I can withdraw from the study at any time and/or refuse to answer any questions, without suffering any negative consequences. If I choose to withdraw, I will have the choice of determining whether all data gathered until the time of withdrawal will be utilized for the study. Should I refuse the utilization of this data, it will not be included in the analysis for the report and will be destroyed immediately.

If I have any questions about the study, I may contact the researcher or her supervisor.

Acceptance: I, _____ agree to participate in the above research study conducted by Sarah-Nicole Simard, University of Ottawa, whose research is under the supervision of Dr. Tracey O’Sullivan of the University of Ottawa.

If I have any questions regarding the ethical conduct of this study, I may contact the Protocol Officer for Ethics in Research, University of Ottawa, Tabaret Hall, 550 Cumberland Street, Room 159, Ottawa, ON K1N 6N5
Tel.: (613) 562-5841
Email: ethics@uottawa.ca

_____ Participant Name	_____ Participant Signature	_____ Date
_____ Primary Investigator	_____ Signature	_____ Date

Appendix H: Consent Form (French)



Université d'Ottawa
Faculté des sciences de la santé

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sciences de la santé

University of Ottawa
Faculty of Health Sciences

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Faculty of Health Sciences,
University of Ottawa
25 University Pwt., Ottawa, ON,
K1N 6N5
Email: hss-adj@uOttawa.ca

A Psychosocial Impact Analysis of a Cancer Coaching Program

Chercheur Principal :
Sarah-Nicole Simard

Superviseur de Thèse :
Dr. Tracey O'Sullivan

L'objectif de l'étude : Le but de l'étude est d'explorer l'impact du programme *Cancer Coaching* mis en œuvre par la Fondation du cancer de la région d'Ottawa sur les survivants du cancer ainsi que les aidants naturels.

Participation : Ma participation consiste en une entrevue de 45 minutes qui, sera réalisée soit à la Fondation du cancer de la région d'Ottawa ou par téléphone à un moment déterminé avec le chercheur. Il me sera demandé de faire des recommandations en ce qui a trait à l'amélioration du programme et des questions sur le système de santé actuel me seront aussi posées. De plus, je devrai fournir des renseignements personnels tels; mon âge, mon occupation et ma situation familiale et de fournir des détails sur mon (ou celui de la personne que je supporte) diagnostic tels que le type de cancer et la phase de celui-ci.

Risques: Ma participation se limite aux discussions en ce qui a trait à mes expériences en tant que participant(e) au programme *Cancer Coaching*. Je comprends que de telles discussions pourraient me causer une angoisse émotionnelle ou psychologique. J'ai reçu de la part des chercheurs l'assurance nécessaire que tous leurs efforts seront déployés afin de minimiser les risques au cas que je me sente inconfortable lors des discussions. J'ai le droit de refuser de répondre à toutes questions qui me sera posé par le chercheur et j'ai aussi le droit d'arrêter l'entrevue en tout temps au cas où je me sens à l'aise. Avant chaque début d'entrevue, je vais recevoir l'information du Program Psychosocial en Oncologie à l'Hôpital d'Ottawa, au cas que je souhaite consulter un psychologue.

Bénéfices: Ma participation dans cette étude va fournir des renseignements notables au sujet des expériences vécues par les participants du programme *Cancer Coaching*. Les résultats, soit négatifs ou positifs, vont représenter la portée du programme ainsi que la faisabilité et la pertinence des interventions pour les jeunes adultes

atteints du cancer. Par ailleurs, cette recherche tente de conceptualiser un modèle qui décrit les impacts psychosociaux qu'un tel programme peut avoir sur ses participants. Par la suite, ce modèle pourrait mener à une future recherche ainsi que des initiatives qui rendrait accessible le programme *Cancer Coaching* pour tous gens atteints de cancer.

Confidentialité et anonymat : J'ai reçu toute l'information nécessaire par le chercheur que les informations divulguées resteront confidentielles. Je comprends que ma confidentialité sera protégée par l'abstention de mon nom de tous les enregistrements vocaux et documents écrits. Aucun nom ne sera divulgué dans l'étude et les citations utilisées dans la recherche seront dénudées de toute information qui pourrait permettre d'identifier le participant.

Sauvegarde des données : Toutes les informations papier seront sauvegardées dans un cabinet barré par clef dans le laboratoire du Dr. Tracey O'Sullivan à l'Université d'Ottawa. Les fichiers électroniques seront protégés par un mot de passe et ne seront qu'accessibles aux chercheurs qui ont un lien direct avec l'étude. Lorsque l'étude sera terminée, les informations compilées seront sauvegardées pour une période 10 ans, pour ensuite être détruites en juin 2024. En ce qui concerne les fichiers électroniques, ils seront effacés de l'ordinateur et les informations papier seront détruites de manière à protéger l'anonymat. La liste des participants ainsi que leurs coordonnées seront aussi débarrassées à ce moment.

Participation volontaire : Je ne suis sous aucune obligation de participer à cette étude. À n'importe quel moment je peux mettre fin à ma participation et/ou refuser de répondre aux questions qui me sont posées sans avoir à craindre une conséquence négative. Dans l'éventualité que je décide de mettre fin à ma participation à l'étude, je dois décider si les informations recueillies jusqu'à présent peuvent être utilisées. Si je refuse, l'information recueillie ne sera pas utilisée dans l'analyse et sera détruite immédiatement avec toutes autres informations recueillies avant la fin de ma participation à l'étude.

Si j'ai des questions par rapport à l'étude, je peux contacter le chercheur ou la superviseure.

(Nom) _____ j'accepte de participer dans la recherche présentée ci-haut dirigée par Sarah-Nicole Simard de l'Université d'Ottawa, qui est sous la supervision du Dr. Tracey O'Sullivan de l'Université d'Ottawa.

Je peux contacter les comités d'éthique en recherche si j'ai des questions d'ordre éthique. Ce comité siège à l'Université d'Ottawa, Tabaret Hall, 550 Cumberland Street, pièce 159.

Ottawa, ON K1N 6N5

Tel.: (613) 562-5841

ethics@uottawa.ca

_____ Nom du Participant	_____ Signature du Participant	_____ Date
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_____ Nom du Chercheur	_____ Signature du Chercheur	_____ Date
---------------------------	---------------------------------	---------------

Appendix I: Demographic Survey (English)

Name: _____

Age: _____

Cancer diagnosis: _____

I was diagnosed (specify when): _____

I completed treatments and became a cancer survivor (specify when): _____

I received coaching sessions while I was (please circle): Newly Diagnosed Receiving Treatments

 Entered Survivorship

I am currently working : ☐ Yes ☐ No *If yes, please check the box(es) that apply.*

☐ Employed (part-time) ☐ Employed (full-time)

Employer: _____

Living Arrangements:

☐ I live with my spouse/partner

☐ I live with spouse/ partner & children☐ I live with my children☐ I live by myself

If you would like to participate and decide to express your interest by mailing back these forms, please provide your telephone number or e-mail address so that I can contact you to schedule an interview date. Otherwise, you can call or e-mail Sarah-Nicole Simard to schedule an interview time & date that is most convenient for you. Thank you very much !

Telephone #: _____

E-mail address:

Appendix: I: Demographic Survey (French)

Nom : _____

Âge : _____ans

Mon diagnostique: _____

Je été diagnostiqué : (veuillez spécifier la date): _____

J'ai rentré en rémission et je suis devenu survivant du cancer (veuillez spécifiez la date) :

J'ai reçu les sessions "coaching" lorsque j'étais (veuillez encercler) :

Nouvellement diagnostiqué

En traitements

En rémission

Je suis présentement employé : ☐ Yes ☐ No *Si oui, veuillez cochez :*☐ Employé (temps partiel) ☐ Employé (temps complet)

Employeur : _____

Situation résidentielle :

☐ Je vis avec un/une conjoint(e)☐ Je vis avec un/une conjoint(e) et mes enfants☐ Je vis avec mes enfants☐ Je vis seul(e)

Si vous aimeriez participez et que vous décidez d'envoyer ces formulaires par la poste, s'il-vous-plaît fournir votre numéro de téléphone ou votre courriel pour que je puisse vous contacter afin de céduer une entrevue. Autrement, vous pouvez exprimer votre intérêt en contactant Sarah-Nicole Simard afin céduer une date qui vous convient le mieux. Merci beaucoup!

Téléphone : _____

Courriel : _____

Appendix J: Interview Guide (English)

1. Can you please describe your transition into the survivorship stage of cancer?

Probe: Explain what it has been like to go through a cancer experience and to transition into being a survivor of cancer.

Probe: Describe how you felt when you initially became a cancer survivor.

Probe: What is your life like now, having been through cancer?

2. I'd like to have examples of common issues individuals encounter once they are declared cancer-free. Can you please describe issues you've encountered as a survivor? (physical, emotional, mental, relational)

Probe: What helped you deal with those challenges?

3. How did you come across the CCP?

Probe: What made you participate in the CCP?

4. When you signed up for the program, what initial goals did you want to accomplish?

5. What measures did you & your coach take to ensure your goals would be accomplished and your needs met?

Probe: Did you accomplish your initial goals?

6. Can you describe the relationship you had with your coach?

Probe: How did your coach support you?

Probe: Describe how you felt working with a cancer coach.

Probe: What did you like the most about your sessions with the coach?

Probe: What could have been improved?

7. Overall, what was your impression of the cancer coaching program?

Probe: What did you like the most and what did you like the least?

8. What are the main outcomes of participating in the CCP?

Probe: What positive or negative changes have occurred since or while participating in the CCP?

9. Describe the most important thing you taken with you from participating in this program?

Probe: What is the most important thing the CCP has given you?

10. What personal strategies have you developed since your participation in the program and how are you applying them?

11. Describe your support network and who has been the most helpful to you.

12. Can you please describe your experience with the health care system (ex: the hospitals, the doctors etc.)

Probe: As a survivor, could you contact your doctors easily if you had questions?

Probe: Do you have any recommendations to make to improve the cancer system?

Probe: What do you think about the organization of support programs for cancer survivors?

13. Please tell me about your experiences accessing the services you need as a cancer survivor.

Probe: What type of information have you needed?

14. Is there anything else you think I should know to understand better the experiences of cancer survivors participating in a CCP?

Annexe J : Interview Questions for Cancer Patient Participant (French)

1. S'il-vous-plaît décrivez votre passage de la maladie à la guérison.

Sonde : Décrivez votre expérience jusqu'à présent.

Sonde : Décrivez comment vous vous êtes sentis.

Sonde : Votre vie aujourd'hui, elle est comment après avoir eu le cancer ?

2. Pouvez-vous me décrire les genres de conflits que vous avez dû surpasser, qu'ils soient physiques, émotionnels, sociales ? J'aimerais avoir une idée quels sont les obstacles les plus prévalent chez les survivants du cancer.

Sonde : Qu'est-ce qui vous a aidé à faire face à ces problèmes ?

3. Comment vous avez découvert le programme ?

4. Quand vous vous êtes inscrits, quels étaient vos buts ?

5. De quelle manière votre coach vous a aidé à accomplir vos buts et quels étapes avez-vous pris pour vous assurer de les accomplir ?

Sonde : Est-ce que vous avez accomplis vos buts initiales ?

6. Pouvez-vous me décrire la relation que vous avez eue avec votre Coach?

Sonde : Comment votre coach vous a supporté ?

Sonde : Décrivez comment vous vous êtes sentis à travailler avec un coach.

Sonde : Quels aspects avec vous le plus aimé de vos sessions?

Sonde : Qu'est-ce qui pourrais être amélioré?

7. En tout, comment décrirez-vous votre expérience avec le programme ?

Sonde : Qu'avez-vous aimé le plus et qu'avez-vous aimé moins bien?

8. Quels sont les principaux résultats obtenus de votre participation au programme?

Sonde : Est-ce que les répercussions ont été positives ou négative depuis votre participation ?

9. Décrivez l'aspect du programme que vous avez le plus retenu.

Sonde : Quel aspect du programme a été pour vous, le plus important?

10. Quelles stratégies avez vous développées depuis votre participation au programme et comment vous les appliquez ?

11. Décrivez votre réseau de soutien et qui vous a été le plus utile.

12. Pouvez-vous s'il vous plaît décrire votre expérience avec le système de santé ? (Par exemple : les hôpitaux, les docteurs, etc.)

Sonde : Que pensez-vous de l'organisation des programmes de soutien pour les survivants du cancer ?

13. S.V.P décrivez votre expérience d'accéder aux services dont vous avez eu de besoins.

Sonde: Quelle information avez-vous eu de besoin ?

14. Y'a-t-il d'autre informations au sujet du programme et des expériences des survivants que vous croyez je dois en savoir plus ?