

Untangling the Relationship Between Fear of Cancer Recurrence and Health Behaviours: A
Nationwide Trajectory and Theoretical Study of Cancer Survivors

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Preface

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General Abstract

Recognized as one of the most prevalent and persistent concerns in cancer survivors, fear of cancer recurrence (FCR) is defined as the "fear, worry, or concern relating to the possibility that cancer will come back or progress" (Lebel et al., 2016). Higher FCR severity leads to poor mental health, impaired functioning and reduced quality of life. It is well established that health behaviours can help reduce the risk of cancer recurrence in cancer survivors, but little is known about their relationship with FCR. The overall thesis objectives were: 1) to identify subgroups of cancer survivors by FCR severity and corresponding patient characteristics; 2) to explore the relationship between FCR and health behaviours (physical activity and fruit and vegetable intake) over time; and 3) to further examine the relationship between FCR severity subgroups and health behaviours using the Common-Sense Model (CSM).

Data analyses were conducted on 2337 survivors of ten cancer sites who completed the American Cancer Society's Studies of Cancer Survivorship-I survey at three time points ($M = 1.3, 2.2, \text{ and } 8.8$ years post-diagnosis). In study 1, group-based trajectory analyses revealed three FCR severity groups: low, moderate, and high. FCR significantly decreased from early to long-term survivorship and remained distinct for each group. Subsequently, repeated measures analysis of variance revealed that patient characteristics prevalent in the high FCR group were being female, of younger age, Hispanic ethnicity, having more advanced cancer stage (II-III) and Non-Hodgkin lymphoma. Across FCR groups, only a minority of survivors adhered to the recommended physical activity and fruit and vegetable intake. Survivors in the high FCR group reported significantly fewer of these health behaviours than other survivors.

In study 2, cross-sectional path analyses were conducted to examine the relationship between FCR and health behaviours using the CSM framework across the FCR severity groups.

Results indicated good-fitting models for the low, moderate, and high FCR groups. Engaging in physical activity and fruit and vegetable intake did not influence FCR in most participants. Yet, in the low FCR group, survivors reporting more health behaviours had lower FCR severity. In the low and moderate FCR groups, health behaviours were related to control over health and self-efficacy to manage health, suggesting that cancer survivors use health behaviours to manage illness outcomes. For survivors in the high FCR group, results suggest that self-efficacy to manage health is a better predictor of FCR than engaging in physical activity and fruit and vegetable intake

In conclusion, most cancer survivors fail to meet the recommended physical activity and fruit and vegetable intake throughout cancer survivorship, with survivors in the high FCR group being at greater risk of engaging in fewer health behaviours. Health behaviours appear unrelated to FCR severity for most cancer survivors, except for survivors with low FCR, who might be experiencing less FCR when engaging in more health behaviours. Findings suggests that clinical interventions should be tailored by FCR severity groups and that health behaviour research among cancer survivors should account for FCR severity groups. Further investigations are required to assess cancer survivors' perceived usefulness of health behaviours to manage the risk of cancer recurrence by FCR severity group.

General Introduction

The diagnosis of cancer is a life changing event that can induce a major physical and psychological stress response. It has been estimated that 1,735,350 new cases of cancer will be diagnosed in America in 2018 and 206,200 cases in Canada in 2018 (Canadian Cancer Society, 2018; Siegel, Miller, & Jemal, 2018). According to the most recent reports on cancer survivors, the most common cancer sites are breast for women (29%), prostate for men (21%), lung for both sexes (female 13% and male 14%), colorectal for both sexes (8%), uterine corpus for women (7%), and bladder for men (6%) (American Cancer Society, 2018). Two in five Canadians are expected to develop cancer in their lifetime, and 60% of these individuals will survive at least five years post diagnosis (Canadian Cancer Society, 2018a). In the United States, the lifetime risk of developing cancer is 39.7% for men and 37.6% for women, and the expected 5-year survival rate is 68% (Siegel et al., 2018).

As cancer death rates consistently drop, the population of cancer survivors is persistently growing (Siegel et al., 2018). Currently, there are approximately 15.5 million cancer survivors in America (American Cancer Society, 2018). Even though their cancer was treated, cancer survivors are left with many unmet needs (Armes et al., 2009) and must face challenges in various aspects of their life, including: fatigue, pain, sleep disruptions, cognitive limitations, low mood, anxiety, financial stress, future planning, and caring for family (Lebel, Rosberger, Edgar, & Devins, 2007; Stalker, Johnson, & Cimma, 1990; Wu & Harden, 2015). Fear of cancer recurrence (FCR) has been recognized as one of the most common concerns among cancer survivors (Simard et al., 2013; Simonelli, Siegel, & Duffy, 2017).

Fear of Cancer Recurrence

Considered a nearly universal theme (O'Neill, 1975), FCR leads to psychological distress

and functional impairment in cancer survivors (Baker, Denniston, Smith, & West, 2005; Herschbach et al., 2004; Lebel et al., 2007). It is defined as the "fear, worry, or concern relating to the possibility that cancer will come back or progress" (Lebel et al., 2016). FCR is a multidimensional concept and manifests itself in different ways, affecting cognitions, behaviours, and emotions (Lee-Jones, Humphris, Dixon, & Bebbington Hatcher, 1997; Simard et al., 2013). To better portray the effect of FCR on cancer survivors, one can imagine the sword of Damocles hanging over the individual's head for the rest of his/her life (Muzzin, Anderson, Figueredo, & Gudelis, 1994).

Establishing FCR Severity

While FCR is a universal theme, it is experienced on a continuum from transient cancer worries to debilitating levels (Mutsaers et al., 2016). The impact of FCR on quality of life and overall functioning is dependent on FCR severity (Simard et al., 2013). Higher FCR severity is associated with psychological distress, depression, anxiety, and impaired quality of life (Hart, Latini, Cowan, Carroll, & Investigators, 2007; Humphris et al., 2003; Koch et al., 2014). Therefore, there is strong empirical evidence that FCR severity is an important predictor of poorer psychosocial outcomes and impairment in functioning in cancer survivors.

There is currently no agreed upon measure or cutoff scores universally used to classify FCR severity (Simonelli, Siegel, & Duffy, 2017). However, cancer survivors are frequently classified in three sub-groups: low, moderate, and high FCR severity. To classify respondents by FCR severity, some studies have used preestablished cutoff scores, or a scoring protocol on specific measures (Fardell et al., 2018; Krok-Schoen, Naughton, Bernardo, Young, & Paskett, 2018; Mehnert, Berg, Henrich, & Herschbach, 2009; Simard & Savard, 2015), while others used statistical cutoffs, such as the median, mean, or standard deviation from the mean (Mehnert,

Koch, Sundermann, & Dinkel, 2013; Melchior et al., 2013; Sarkar et al., 2014). Overall, there is little consistency in the literature on the best method to classify cancer survivors by low, moderate, or high FCR severity. Furthermore, it is unclear what FCR severity constitutes “clinical” levels of FCR.

Clinical FCR. As opposed to classifying FCR severity in three sub-groups, some studies have focused on screening cancer survivors with “clinical” levels of FCR. Clinical FCR is associated with lower quality of life, greater psychological distress, functional impairment and psychiatric disorders (i.e., depression, panic disorder, and generalized anxiety), than survivors with non-clinical FCR levels (Hart et al., 2007; Humphris et al., 2003; Sarkar et al., 2014; Simard et al., 2013). In addition, these cancer survivors use more health care resources, including outpatient and emergency department visits, and increased use of medication (Lebel, Tomei, Feldstain, Beattie, & McCallum, 2013). Untreated FCR can therefore put a strain on health care demands and cost.

Given the highly debilitating nature of clinical levels of FCR, clinical FCR is an important topic of research in the psychosocial oncology field (Sharpe, Thewes, & Butow, 2017). Yet, there is no consensus on the core features of clinical FCR (Lebel et al., 2016; Mutsaers et al., 2016; Simard & Savard, 2015). However, five clinical features were proposed by a team of experts on FCR: 1) high levels of preoccupation, worry, rumination, or intrusive thoughts, 2) maladaptive coping, 3) functional impairments, 4) excessive distress, and 5) difficulties making plans for the future (Lebel et al., 2016).

Similarly, to FCR severity, there is no universal measurement method to screen for clinical FCR, and no agreed-upon cut-off scores for clinical FCR. For example, separate research groups found different cut off scores on the Fear of Cancer Recurrence Inventory-Short Form

(FCRI-SF), a frequently used screening instruments of clinical FCR (Simard & Savard, 2009; Thewes et al., 2012). While the initial cut-off score was found to be 13 (Simard & Savard, 2009), additional studies suggest that scores of 16 and 22 were better indicators of clinical FCR levels (Fardell et al., 2018). In sum, FCR is an important predictor of psychosocial outcomes in survivorship but severity and clinical threshold remain to be determined.

Prevalence and Trajectory of FCR

Given the aforementioned inconsistencies in the measurement of FCR (Simonelli et al., 2017), the prevalence of FCR severity across time remains unclear. The studies that explored this topic yielded heterogenous results. From diagnosis to early survivorship (i.e. two years post active treatment; Stanton, Rowland, & Ganz, 2015) a wide-range of prevalence were observed across studies: 15-76% of cancer patients reported low FCR, 40-68% moderate FCR, and 9%-56% high FCR (Halbach et al., 2016; Krok-Schoen, Naughton, Bernardo, Young, & Paskett, 2018; Mehnert, Koch, Sundermann, & Dinkel, 2013; Ratcliff, Naik, Martin, & Moye, 2017; Sarkar et al., 2014; Savard & Ivers, 2013). A clearer picture has emerged in studies looking at FCR prevalence later in the cancer survivorship trajectory (i.e., 5-8 years post diagnosis). These have reported rates of 76-87% for low FCR, 9-15% for moderate FCR, and 4-9% for high FCR (Koch et al., 2014; Koch-Gallenkamp et al., 2016; Mehnert et al., 2013).

A literature review looking at FCR in long-term cancer survivors, defined as 5 years post diagnosis, found that most cancer survivors continue to experience FCR over an extensive period after cancer diagnosis, and the authors concluded that FCR remains stable overtime (Koch, Jansen, Brenner, & Arndt, 2013). However, most findings are limited by their cross-sectional design (Koch et al., 2013; Simonelli et al., 2017). The few longitudinal studies currently available are limited to 2 years post-diagnosis and indicate that FCR is stable over time (Crist &

Grunfeld, 2013; Koch et al., 2013; Simard et al., 2013; Simonelli et al., 2017), but other recent studies have found FCR severity to significantly decrease over time (Dunn et al., 2015; Halbach et al., 2016; Mehnert et al., 2013; Sarkar et al., 2014). To explain these contradictory findings, authors offered a nuanced conclusion, stating that while FCR significantly decreased in the survivorship trajectory, the effect size was small, therefore most cancer survivors continued to persistently experience FCR. (Melchior et al., 2013). Furthermore, Dunn and colleagues (2015) found that the relationship between FCR and time was best described by a quadratic trend, where FCR steeply decreased in early survivorship and stabilized over time. These studies did not take into consideration distinct FCR trajectories within their samples which could explain the mixed findings.

Interestingly, two studies of survivors from diagnosis to 12-18 months post diagnosis found a greater decrease in FCR among higher FCR groups in comparison to low FCR groups (Melchior et al., 2013; Savard & Ivers, 2013). Therefore, there is preliminary evidence that subgroups of cancer survivors follow distinct patterns of FCR changes over time depending on FCR severity (Melchior et al., 2013; Savard & Ivers, 2013). An additional limitation of the previous longitudinal FCR studies is that they were conducted with one cancer site (predominantly breast), which limits generalizability across cancer sites. Given the inconsistent prevalence results and the limited longitudinal studies looking at FCR trajectories, additional analyses are needed to look at FCR trajectories from early to long-term survivorship, across more than one disease site. In addition to the influence of time, some patient characteristics have been found to predict FCR severity.

Socio-Demographic Predictors of FCR

Across studies, younger age is consistently associated with higher FCR in cancer

survivors (Crist & Grunfeld, 2013; Koch et al., 2013; Simard et al., 2013; Simonelli et al., 2017). In contrast, there is moderate evidence that sex, educational status and ethnicity are related to FCR severity (Crist & Grunfeld, 2013; Simard et al., 2013). While most studies have found that women tend to experience more FCR than men, some studies have found no sex differences (Crist & Grunfeld, 2013; Simard et al., 2013). According to most studies, education status is unrelated to FCR, however a few studies have found that lower education is related to higher FCR (Simard et al., 2013). Regarding ethnicity, there is emerging evidence that Afro-American cancer survivors experience less FCR than Caucasians and Hispanics, and that Hispanic cancer survivors tend to report higher FCR severity than other ethnicities (Crist & Grunfeld, 2013; Simard et al., 2013), however most studies concluded that ethnicity did not predict FCR severity. Furthermore, income and employment status yielded contradictory findings, while most studies found no association with FCR, a few studies found that being employed and having a lower income predicts higher FCR (Crist & Grunfeld, 2013; Simard et al., 2013). There is general consensus that marital status is unrelated to FCR (Crist & Grunfeld, 2013; Simard et al., 2013). Interestingly, there is weak evidence that medical and treatment variables predict FCR severity (Koch-Gallenkamp et al., 2016; Savard & Ivers, 2013; van de Wal, van de Poll-Franse, Prins, & Gielissen, 2016). This suggests that FCR manifests similarly across cancer sites and stage.

FCR Theoretical Formulation

Leventhal's Common-Sense Model (CSM) (Leventhal, Diefenbach, & Leventhal, 1992) is the most comprehensive and evidenced-based theoretical approach applied to FCR (Fardell et al., 2016). In a seminal paper published by Lee-Jones et al. (1997) a theoretical FCR formulation was elaborated using components of CSM. The model was used to conceptualize the multidimensional construct of FCR, integrating cognitions, behaviours, and emotions. The CSM

continues to influence emerging FCR blended models (Fardell et al., 2016; Lebel et al., 2014; Simonelli et al., 2017) and inform FCR interventions (Butow et al., 2017; Lebel et al., 2014; Maheu et al., 2016; Tomei, Lebel, Maheu, & Mutsaers, 2016).

Leventhal Common-Sense Model

The CSM, also known as the Self-Regulation Model of Illness, is a theoretical model initially developed to predict adherence to a medical regimen (Leventhal et al., 1992). It stipulates that all individuals formulate their own illness representation by combining information from three sources: previously assimilated lay information (e.g. personal experience with illness), external social sources of information (e.g. doctor recommendations, media, etc.), and current experience with the illness. When an illness threat is perceived, it simultaneously activates the individual's illness representation consisting of two processing systems: cognitive and emotional which work in parallel to inform coping responses (see figure 1). Following the implementation of the coping responses, it will be appraised via interpretation of illness/emotional outcomes. The appraisal of coping completes a feedback loop which will inform future coping strategies should the illness threat return. The cognitive and emotional interpretations mutually influence each other, which may lead to excessive distress, which is later reinforced by the feedback loop and maintains anxiety.

The CSM was chosen for this study as it is the most comprehensive and empirically validated model applied to FCR (Fardell et al., 2016). Additionally, the model was developed to predict health behaviours in chronically ill patients (Leventhal et al., 1992). Thus, it was determined to be the most appropriate model to investigate the relationship between health behaviours and FCR. With that said, other health psychology models are commonly used to predict behaviour in chronically ill patients.

Other Health Psychology Models

The following section is an overview of other health psychology models often applied to chronically ill individuals.

Transactional Model of Stress. The Transactional Model of Stress elucidates the interplay between personal and environmental variables in the process of facing life stressors (Lazarus & Folkman, 1987). The theory stipulates that individuals facing stressful situations engage in primary and secondary appraisal. The primary appraisal is helpful to identify the relevance of the potential stressor on personal well-being. Thus, individuals qualify the stress in one of the following three types: *harm*, the stress has been previously experienced as harmful, *threat*, anticipated harm, or *challenge*, potential for mastery or gain if the individual effectively copes with the stress. The secondary appraisal is a cognitive process enabling individuals to assess their coping options, considering their abilities and level of control over the outcomes. The primary and secondary appraisals influence each other and mediate the emotional reaction to the stressor in a recursive pattern with no particular order. This process determines if the relationship between personal antecedent trait variable (ex. values, beliefs, and goals) and the environmental transactional variables (ex. demands, resources and temporal aspects) warrants action and how one might cope with this stressor.

The coping behaviour will then impact short-term (ex. affect and physiological response) and long-term outcomes (ex. quality of life, health status). Moreover, Lazarus and Folkman, posit that coping has two main functions: the first, to manage the aforementioned person-environment relationship (stressor) known as problem-focused coping and the second, to regulate emotional distress, known as emotion-focused coping. Lazarus and Folkman found that appraising a stressor as modifiable tends to elicit problem-focused coping, meanwhile emotion-

coping is favoured when a stressor is deemed unchangeable therefore requiring acceptance. This coping conceptualisation is consistently observed in recent studies of chronically ill individuals (Hagger et al., 2017; Richardson, Schüz, Sanderson, Scott, & Schüz, 2016).

Health Belief Model. According to the Health Belief Model, the likelihood of engaging in health behaviour is dependent on four factors: the *perceived susceptibility* and *perceived seriousness* of health threat, the *perceived benefit vs. barriers* to engaging in the health behaviour, the *perceived self-efficacy*, and *cue to action* (Becker, 1974; Rosenstock, 1974). The model stipulates that patients who feel personally vulnerable to the health threat, perceive severe consequences of illness, believe that the benefits of engaging the health behaviour outweigh the costs (barriers), and have greater self-efficacy for this specific behaviour are more likely to engage in health behaviours. Internal or external triggers will then act as cues to action, motivating patients to engage in the health behaviours. It is thought that the nature of the cue to action will impact the other factors in the model determining the level of engagement in health behaviour.

Theory of Planned Behaviour. Theory of Planned Behaviour puts forth that the individual's *intention* to engage in a behaviour is the central factor predicting achievement of *behaviour* (Ajzen, 1991). It is assumed that the stronger the intention, the greater the chances of engaging in the behaviour. However, this relationship is only true if the intent reflects the individual's volition, meaning that the decisional control to engage in the behaviour resides with the individual and not prescribed by an external source. Upstream are three factors predicting the level of intention: *attitudes towards the behaviour* (positive or negative evaluation of the behaviour), the *subjective norms* (social norms and pressures to perform the behaviour), and *perceived behavioural control* (subjective evaluation of the individual's ability to achieve the

behaviour with ease or difficulty). The Theory of Planned Behaviour posits that a favorable attitude, combined with a greater perceived support from others and a greater perceived control to engage in the behaviour will predict stronger intention to perform the behaviour. Furthermore, the perceived behavioural control also has a direct effect on the behaviour given that self-efficacy to perform a behaviour in addition to strong intentions leads to a greater probability of health behaviour achievement.

The Transtheoretical Model of Health Behaviour Change. The Transtheoretical Model of Health Behaviour Change is a temporal model of change commonly used in health psychology. The purpose of the model is to combine previously known psychological processes and principles of change into one integrated model, hence the name transtheoretical (Prochaska & Velicer, 1997). The model posits that the progress of health behaviour change is a process through six stages: precontemplation, contemplation, preparation, action, maintenance, and termination.

Patients in the *precontemplation* stage have no intention of changing their health behaviours, for some this is related to a lack of education and for others a dejection of their ability to change. These patients are often described as not ready for therapy and most health promoting interventions are ill-equipped to help these patients.

In the *contemplation* stage, patients show intent to change in the next 6 months. They are often ambivalent as they weight out the pros and cons of modifying their behaviours. Some individuals can remain stuck in this stage for long periods of time as they continuously contemplate. Although these patients can recognize the benefit of the health behaviour change, they are not ready to act.

Patients in the *preparation* stage are intending on engaging in health behaviours in the

near future. They are prime candidates to action-oriented interventions, that will support them in making plans to carry out the health behaviour change.

The *action* stage consists of patients who have been making health changes in the last 6 months. The health behaviour change must achieve a significant degree of health risk reduction, as qualified by a scientist or health care practitioner.

In the *maintenance* stage, patients continue to maintain health behaviour changes and work on relapse prevention. Relapse is commonly seen in health behaviour changes and is qualified as any return to a previous stage. With that said, most patients will recover from a relapse and find themselves engaging in another attempt at action. It is also true that for some, a relapse will lead to a return in the precontemplation stage, where they might be demoralized by the idea of attempting the health change again.

Finally, in the *termination* stage, patients are thought to have no temptation and have enough self-efficacy to maintain the health behaviour throughout their life regardless of challenges ahead. Little research has been conducted on these patients as it is not the reality for most patients.

Although these health models are helpful to predict health behaviour in chronically ill individuals, the Common-Sense Model remains the most empirically validated model applied to FCR which also predicts health behaviours in cancer survivors (Lee-Jones et al., 1997).

Common-Sense Model for FCR

Lee-Jones et al. 1997 further refined to CSM and applied it specifically to FCR (see figure 2). They suggested that FCR is a multidimensional construct, involving both the cognitive and emotional processing systems. This theoretical FCR formulation stipulates that external and internal triggers (illness threat) activate cancer survivors' illness perception about cancer

predicting perceived risk of cancer recurrence, inherently influencing the coping response, which will be appraised to determine the efficacy of coping and subsequently influence FCR (Fardell et al., 2016; Lee-Jones et al., 1997).

Triggers. In the context of cancer, illness threats are understood in two categories: internal triggers (e.g. aches and pain), and external triggers (e.g. attending cancer screening or medical appointment or hearing about cancer in the media) (Lee-Jones et al., 1997). The relationship between external and internal triggers and the illness representation was empirically validated (Easterling & Leventhal, 1989). Moreover, cancer survivors who perceive a high risk of cancer recurrence tend to be more emotionally aroused by somatic stimuli (Easterling & Leventhal, 1989; Lee-Jones et al., 1997; Llewellyn, Weinman, McGurk, & Humphris, 2008).

Illness representation. As described in the CSM, the illness representation is comprised of five illness attributes; *illness identity* – refers to the illness label (cancer) and related symptoms (e.g. fatigue), *consequences* – refers to the perceived impact of cancer on an individual's life, including social, psychological and physical consequences (e.g., impact on family), *control* – refers to the perceived level of control over cancer or curability by oneself or others (e.g. incurable, recurrence preventable), *timeline* – refers to the perceived time frame of cancer growth, illness course, and recovery (e.g., acute, chronic, or cyclical) and *causes* – refers to the perceived cause of cancer (e.g. stress, unhealthy lifestyle, or family history), (Cameron & Leventhal, 2003). According to CSM, the constellation of these attributes will predict the perceived risk of cancer recurrence and inform the coping response chosen by the patient to manage emotional (emotion focused coping) or illness outcomes (problem-focused coping) (Hagger, Koch, Chatzisarantis, & Orbell, 2017). Higher perceived risk of cancer recurrence has been shown to elucidate coping responses to manage emotional outcomes, such as FCR (Lee-

Jones et al., 1997). In chronically ill patient samples, illness identity, consequences, and timeline have been shown to predict emotion-focused coping, while perceived control over health and appraisal of coping were strongly related to problem-focused coping (Hagger et al., 2017; Richardson, Schüz, Sanderson, Scott, & Schüz, 2016).

Coping response, appraisal, and FCR. Body checking, reassurance seeking, and avoidance are recognized as the three most common coping responses to perceived risk of cancer recurrence in cancer survivors (Simard et al., 2013). While attending regular doctor's appointments, completing screening tests, and checking body parts for abnormalities are recommended practices for cancer patients (Canadian Cancer Society, 2018b; National Cancer Institute, 2018), they can become maladaptive when excessively used to manage fear or worries related to cancer recurrence (Simard, Savard, & Ivers, 2010). Similarly, excessively relying on avoidance to manage perceived risk of cancer recurrence predicts higher FCR. While these coping responses provide temporary relief by appeasing one's perceived risk of cancer recurrence, they can inherently increase FCR over time by feeding vigilance and reinforcing worries (Langlois, Ladouceur, Patrick, & Freeston, 2004; Lee-Jones et al., 1997; Simard et al., 2010). Unsurprisingly, the excessive use of coping behaviours are commonly found in cancer survivors with moderate to high FCR severity (Simard et al., 2013).

Current Limitations. As the CSM continues to influence FCR formulations and subsequent interventions, it is important that future studies address some of the current limitations (Richardson, Schüz, Sanderson, Scott, & Schüz, 2017). As previously mentioned, there is emerging empirical evidence that cancer survivors can be classified into three FCR severity subgroups: low, moderate, and high. Cancer survivors in these three groups have distinct characteristics (Simard & Savard, 2009; Simonelli et al., 2017). Thus far, studies on FCR using

the CSM have either overlooked FCR sub-groups or focused solely on the high FCR subgroup using clinical samples (Butow et al., 2017; Corter, Findlay, Broom, Porter, & Petrie, 2013; Lebel et al., 2014). Moreover, these studies were conducted with one or only a few cancer sites, limiting generalizability across sites (Richardson et al., 2017). Therefore, current findings might not encompass the full extent of responses to the perceived risk of cancer recurrence in cancer survivors. Additionally, in FCR research, health behaviours as a response to illness representation of cancer has been understudied and warrants further investigation.

Health Behaviours as a Coping Response. While the CSM was initially elaborated to predict adherence to medical regimen, including health behaviours (Cameron & Leventhal, 2003), only a few studies have looked at the relationship between health behaviours and FCR using the CSM framework (Burris, Jacobsen, Loftus, & Andrykowski, 2012; Costanzo, Lutgendorf, & Roeder, 2011; Green, Steinnagel, Morris, & Laakso, 2014; McGinty, Goldenberg, & Jacobsen, 2012; Mullens, McCaul, Erickson, & Sandgren, 2004). In the CSM literature, health behaviours are generally conceptualized as problem-focused coping to manage illness outcomes (Hagger et al., 2017; Richardson et al., 2016), however they have been shown to help manage emotional outcomes such as depression and quality of life (Aguñaga et al., 2018). Investigating the relationship between FCR and health behaviours is the first step to examine if health behaviours are adaptive coping responses to manage FCR. The next section provides an overview of health behaviours in the context of cancer survivorship.

Health Behaviours in Cancer Survivors

Following cancer diagnosis and across the survivorship trajectory, cancer survivors are encouraged to engage in health behaviours and to maintain a healthy lifestyle (Costanzo et al., 2011). Health behaviours are defined as "any action taken to restore, maintain, or improve health

and to prevent illness" (Park & Gaffey, 2007). Although, 88% of cancer survivors report making at least one positive behaviour change since cancer diagnosis (Hawkins et al., 2010), most cancer survivors do not meet health behaviour recommendations (Demark-Wahnefried et al., 2015).

Health Behaviour Recommendations

There is a growing body of evidence demonstrating that lifestyle changes have a countering effect on cancer progression/recurrence and promote healthy survivorship (Davies, Batehup, & Thomas, 2011; Pekmezi & Demark-Wahnefried, 2011). Smoking cessation, limiting alcohol intake, eating fruits and vegetables, consuming a low-fat diet, losing weight or maintaining a healthy weight, being physically active, and reducing sun exposure are recommended to help prevent cancer recurrence (Canadian Cancer Society, 2018b; National Cancer Institute, 2018). More precisely, physical activity and dietary changes have been shown to improve cancer survivor's health by managing excess body weight, an important risk factor for cancer. Furthermore, regular physical activity and maintaining a healthy diet improves cancer patients' overall wellbeing and quality of life (Blanchard, Courneya, & Stein, 2008; Breedveld-Peters et al., 2018; Demark-Wahnefried et al., 2018).

Physical activity and diet recommendations. This thesis will focus on physical activity and fruit and vegetable intake in cancer survivors, given that these health behaviours are the most important modifiable determinants of cancer risk for non-tabacco users (Kushi et al., 2012). Smoking cessation was excluded from the thesis, as the data was being analyzed by another team working with the same data set. In 2003, the American Cancer Society (ACS) published their first report summarizing the scientific evidence and best clinical practices for health care providers, cancer patients, and their families regarding the optimal nutrition and physical activity after cancer diagnosis (Brown et al., 2003). Among the health behaviour guidelines, the report

stated that cancer survivors should engage in at least 30 minutes of moderate to vigorous physical activity on five or more days each week and eat five servings of fruits and vegetables each day. In the 2012 updated report, the ACS published similar recommendations: 150 minutes of moderate physical activity or 75 minutes of vigorous physical activity weekly and the intake of at least five portions (5-a-day) of fruits and vegetables each day (Kushi et al., 2012). Despite these recommendations, most cancer survivors do not adhere to these health behaviours (Demark-Wahnefried et al., 2015).

Physical activity and Fruit & Vegetable Intake in Cancer Survivors

Prevalence. Across various cancer sites, less than half of north American cancer survivors meet the ACS physical activity guidelines with prevalence ranging from 14-49% (Blanchard et al., 2008; Bluethmann et al., 2015; Brunet, Amireault, Chaiton, & Sabiston, 2014; M. L. Hawkins et al., 2017; LeMasters, Madhavan, Sambamoorthi, & Kurian, 2014). Similarly, the percentage of cancer survivors meeting the recommended fruit and vegetable intake ranged between 14-51% (Blanchard et al., 2008; Bluethmann et al., 2015; LeMasters et al., 2014). Moreover, samples of cancer survivor were found to engage in less health behaviours than healthy samples (Blanchard et al., 2008; M. L. Hawkins et al., 2017; Williams, Steptoe, & Wardle, 2013).

Adherence over time. Although, there are many cross-sectional studies looking at physical activity and diet in cancer survivors, the longitudinal studies looking at health behaviour changes over time are sparse. Two longitudinal studies found no significant change in cancer survivor's physical activity from initial diagnosis to 3 months, and 4 years post-diagnosis. (Costanzo et al., 2011; Williams et al., 2013). While the first study was conducted with breast cancer survivors, the second did not specify the cancer site. Interestingly, one study conducted

with breast cancer survivors found five different trajectories describing changes in physical activity within the first-year post cancer diagnosis, showing that cancer survivors may not uniformly engage in physical activity (Brunet et al., 2014) . Within these groups, there appears to be a subset of cancer survivors who report an important change in physical activity across time but there were no formal statistical tests conducted to look at changes over time. In terms of diet, one longitudinal study on breast cancer survivors found no significant change in fruit and vegetable intake in early survivorship (Costanzo et al., 2011). There is a lack of longitudinal study looking at changes in physical activity and fruit and vegetable intake over time (Bluethmann et al., 2015; Brunet et al., 2014). In addition, no studies span from early to long-term survivorship. Moreover, longitudinal data is limited to one cancer site, limiting generalizability across cancer sites.

Socio-demographic predictors of health behaviours. Across cancer types, younger male cancer survivors diagnosed with advanced cancer for a longer time span and who have higher education engage in more physical activity (Kanera et al., 2016; Parelkar, Thompson, Kaw, Miner, & Stein, 2013; Park, Edmondson, Fenster, & Blank, 2008; Park & Gaffey, 2007). Likewise, being a younger cancer survivor diagnosed with advanced cancer for a longer time span and with higher education is related to a healthy diet (including fruit and vegetable intake) across cancer sites (Kanera et al., 2016; Parelkar et al., 2013; Park et al., 2008; Park & Gaffey, 2007).

Influence of FCR on Physical Activity and Fruit and Vegetable Intake

Cancer is commonly conceptualized as a "teachable moment", motivating cancer survivors to engage in physical activity and fruit & vegetable intake to reduce the risk of cancer recurrence and improve overall health (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005).

Moreover, in Lee-Jones' model, FCR is conceptualized as a motivating factor promoting health behaviours. In the last decade, only a few studies have looked at the association between FCR and physical activity and dietary changes in cancer survivors (Fisher, Beeken, Heinrich, Williams, & Wardle, 2016). Overall, studies have yielded conflicting results. While some studies have found no significant association between FCR and physical activity or diet (Alfano et al., 2009; Burris et al., 2012; Mosher et al., 2008), one study found a negative relationship with higher FCR predicting less physical activity (Fisher et al., 2016), and two studies found that higher FCR was associated with an increase in physical activity and positive dietary changes (Hawkins et al., 2010; Maunsell, Drolet, Brisson, Robert, & Deschênes, 2002). Given these mixed findings, more research is needed to clarify the influence of FCR on health behaviours.

Applying the CSM framework. As mentioned previously, the CSM was initially elaborated to predict adherence to health behaviours in chronically ill patients (Cameron & Leventhal, 2003). As stipulated in the Lee-Jones et al. FCR formulation, illness representation is expected to influence engagement in physical activity and fruit and vegetable intake, which will be appraised and subsequently influence FCR severity.

A few studies have used the CSM framework to test the relationship between perceived risk of cancer recurrence, physical activity and fruit and vegetable intake (Burris et al., 2012; Costanzo et al., 2011; Green et al., 2014; McGinty et al., 2012; Mullens et al., 2004). However, the mixed results in the literature may be attributed to inconsistencies in how health behaviour constructs were measured across studies. Studies measuring self-report changes or intent to engage in health behaviours generally found a significant association between perceived risk of cancer recurrence and health behaviours (Burris et al., 2012; Costanzo et al., 2011; Green et al., 2014; Mullens et al., 2004). However, this association was not found when adherence to health

behaviours was measured using validated health behaviour measures (Burriss et al., 2012; Green et al., 2014; McGinty et al., 2012; Mullens et al., 2004).

Illness representation and health behaviours. When looking at self-report changes in health behaviours, one study of breast cancer survivors found that severity of perceived cancer consequences, causal attribution of cancer to poor diet or lack of exercise, and beliefs that physical activity/healthy diet can prevent recurrence predicted more physical activity and increase in fruit and vegetable intake. Yet, personal control and illness timeline did not significantly predict self-report changes in health behaviours (Costanzo et al., 2011). In another study of breast and prostate cancer survivors, conflicting conclusions were drawn, where greater personal control and illness identity was associated with self-reported increase in physical activity and healthier eating (Green et al., 2014). In terms of adherence to physical activity and healthy diet, beliefs that health behaviours can prevent cancer and contribute to overall good health was predictive of health behaviours (Burriss et al., 2012; Mullens et al., 2004)

Appraisal and FCR. Another important component of the CSM is the individual's appraisal of the coping. One longitudinal study of 161 breast cancer survivors found that the interaction between higher perceived risk of cancer recurrence and negative appraisal of health behaviour efficacy significantly predicted higher FCR severity. However, on its own, appraisal was not associated with FCR severity (McGinty et al., 2012). While the research on appraisal of coping is sparse, the perceived self-efficacy to engage in health behaviours, a similar construct, is more frequently measured. A few studies found that perceived self-efficacy to complete physical activity and dietary recommendations, was associated with adherence to health behaviours (Burriss et al., 2012; Green et al., 2014; Mullens et al., 2004).

While these studies began the meticulous task of uncovering the relationship between

FCR and health behaviours using the CSM, they are restricted to one or two disease sites, confined to early survivorship (i.e. two years post active treatment), and some are limited by subjective measures of health behaviours. Further investigations are required to clarify the contradictory findings using a large sample of mixed cancer survivors.

Current Studies

Rational for the Current Thesis

FCR is one of the most common concerns reported by cancer survivors. FCR severity can range from normative to clinical levels, impacting survivors' psychosocial functioning and quality of life (Simard et al., 2013). Therefore, classifying cancer survivors by FCR severity groups is a necessary first step to adequately screen survivors at risk of poor psychological outcomes. Although, there is strong empirical evidence that health behaviours can help prevent cancer recurrence and improve overall health, most cancer survivors do not adhere to physical activity and fruit and vegetable intake guidelines. Therefore, investigating the uptake of health behaviours over time, and shedding light on their relationship with FCR severity is crucial.

The CSM is the most comprehensive and evidenced-based theoretical approach applied to FCR. Commonly used to predict health behaviours in chronically ill patients, the CSM is the most appropriate theoretical framework to examine the relationship between health behaviours (physical activity and fruit and vegetable intake) and FCR. Moreover, as the CSM continues to influence FCR models and subsequent interventions, empirically examining the role of health behaviours within the model is imperative. While examining this relationship, taking into consideration FCR severity sub-groups is key to adequately capture the full range of FCR manifestation in cancer survivors.

Overview of the Current Studies

The aim of this thesis is to examine the relationship between FCR and health behaviours using a large population-based sample of survivors of ten cancer sites. This thesis consists of two studies. In the first study, a longitudinal design (over three timepoints) was used to identify FCR trajectory groups and assess health behaviour practices (physical activity and fruit and vegetable intake) within groups from early to long-term survivorship. The second study was a cross-sectional design using data from the third timepoint. Taking into consideration the FCR trajectory groups identified in study 1, the relationship between health behaviours (physical activity and fruit and vegetable intake) and FCR was examined using the CSM's theoretical formulation of FCR.

Both studies used secondary data from the American Cancer Society's Study of Cancer Survivors-I (SCS-I), a national prospective longitudinal study of American cancer survivors. Questionnaire packages were administered in three waves from early to long-term survivorship. The questionnaire packages were slightly modified between administrations to include recent measurement tools, therefore not all questionnaires were available at all three time points. The purpose of the survey was to collect data to examine quality of life in American cancer survivors (Smith et al., 2007). Participants were recruited from 25 randomly selected cancer registries across the United States. Participant eligibility criteria were the following: diagnosed with one of the ten most highly incident cancers (prostate, breast, lung, colorectal, bladder, non-Hodgkin lymphoma (NHL), skin melanoma, kidney, ovarian, and uterine), over 18 years old at diagnosis, residing in one of the target states at the time of diagnosis, and diagnosed with a local, regional, or distant SEER Summary Stage cancer. Survivors were ineligible for the study if they were unable to complete the survey due to mental incompetence, unable to communicate in English or

Spanish, or had terminal illness (Smith et al., 2007). The studies were approved by the Institutional Review Board of Emory University (Atlanta, GA), for each state, including the Connecticut Department of Public Health Human Investigation Committee, and the University of Ottawa Research and Ethics Board (Ottawa, Ontario).

Study 1 - Untangling the Relationship Between Fear of Cancer Recurrence and Health Behaviours: a Nationwide Longitudinal Study of Cancer Survivors

The purpose of the first study was to clarify the relationship between FCR and health behaviours (physical activity and fruit and vegetable intake) from early to long-term survivorship.

1) The first objective was to identify distinct longitudinal FCR trajectories, by clustering cancer survivors following a similar FCR progression. FCR severity and patient characteristics associated with each trajectory group were then formally compared. The authors hypothesised that three distinct FCR trajectories: low, moderate, and high FCR would be identified. FCR was hypothesised to significantly decrease over time across all three trajectories but the higher FCR group was expected to show a greater reduction in FCR than the other groups. Patients with the following characteristics: younger age, female, Hispanic ethnicity, and high school education or less were expected to be more prevalent in the high FCR group. Given the weak evidence, no hypotheses were noted regarding cancer stage or cancer site between trajectory groups.

2) The second objective was to explore the physical activity and fruit and vegetable intake reported by cancer survivors, first by comparing these behaviours between trajectory groups and over time, and second by establishing the rate of adherence to recommended health behaviours and comparing them by trajectory group. The high FCR group was expected to report more physical activity and fruit and vegetable intake than the moderate and low FCR groups.

Moreover, as FCR decreases over time physical activity and fruit and vegetable intake was expected to also decrease across time in all three trajectory groups. This manuscript was accepted by Health Psychology, in March, 2019 .

Study 2 – Can Physical Activity and Healthy Diet Help Cancer Survivors Manage their Fear of Cancer Recurrence?

Using the CSM's theoretical formulation of FCR, this cross-sectional study aimed to explore the relationship between health behaviours (physical activity and fruit and vegetable intake) and FCR in a population-based sample of 10 cancer sites categorised by FCR severity groups (see figure 1). With the conceptualization that physical activity and fruit and vegetable as a coping response to FCR, the following relationship in the CSM were expected.

1) The authors hypothesized the following relationships between illness representation attributes and health behaviours (physical activity and fruit and vegetable intake): a- Illness identity & Consequences: cancer survivors who had a worse perception of their health and illness consequences were expected to report more health behaviours. b- Control over health: survivors who perceived more control over their health were expected to report more health behaviours. c- Timeline: survivors who viewed cancer as chronic were expected to report more health behaviours.

2) Health behaviours – appraisal: survivors who report more health behaviours were expected to positively appraise their self-efficacy to manage health.

3) Appraisal – FCR: survivors who positively appraise their self-efficacy to manage health were expected to have lower FCR severity.

Overall, the hypothesized model was expected to show a good fit across FCR severity groups. The authors had no hypotheses concerning specific paths by FCR group, given that this

is the first study to distinguish between FCR groups when testing the CSM. The authors hypothesised similar trends for both health behaviours; physical activity and fruit and vegetable intake (Burris et al., 2012; Costanzo et al., 2011; Green et al., 2014; Mullens et al., 2004).

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General Introduction Figures

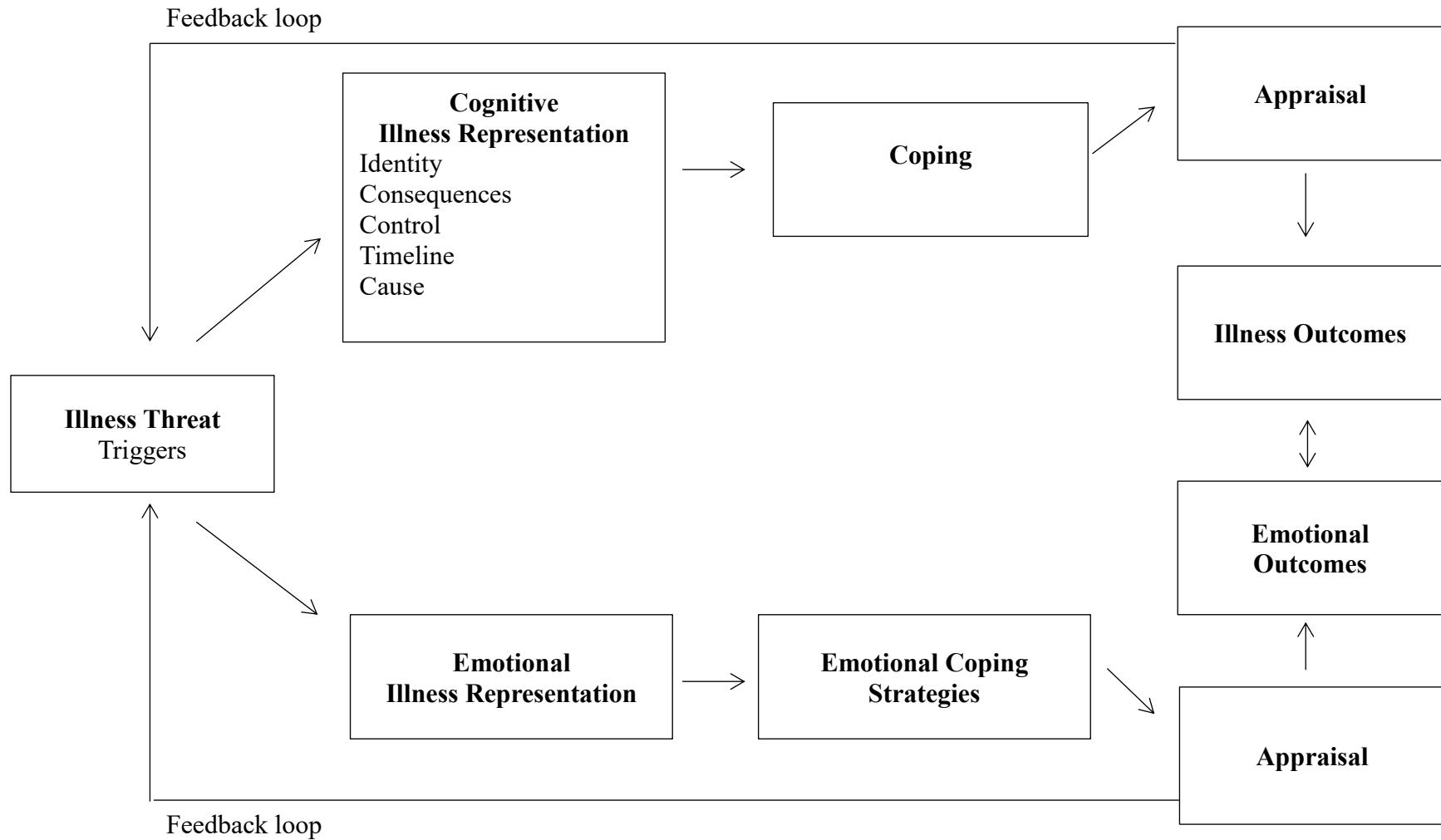


Figure 1: Leventhal Common-Sense Model (Leventhal et al., 1992)

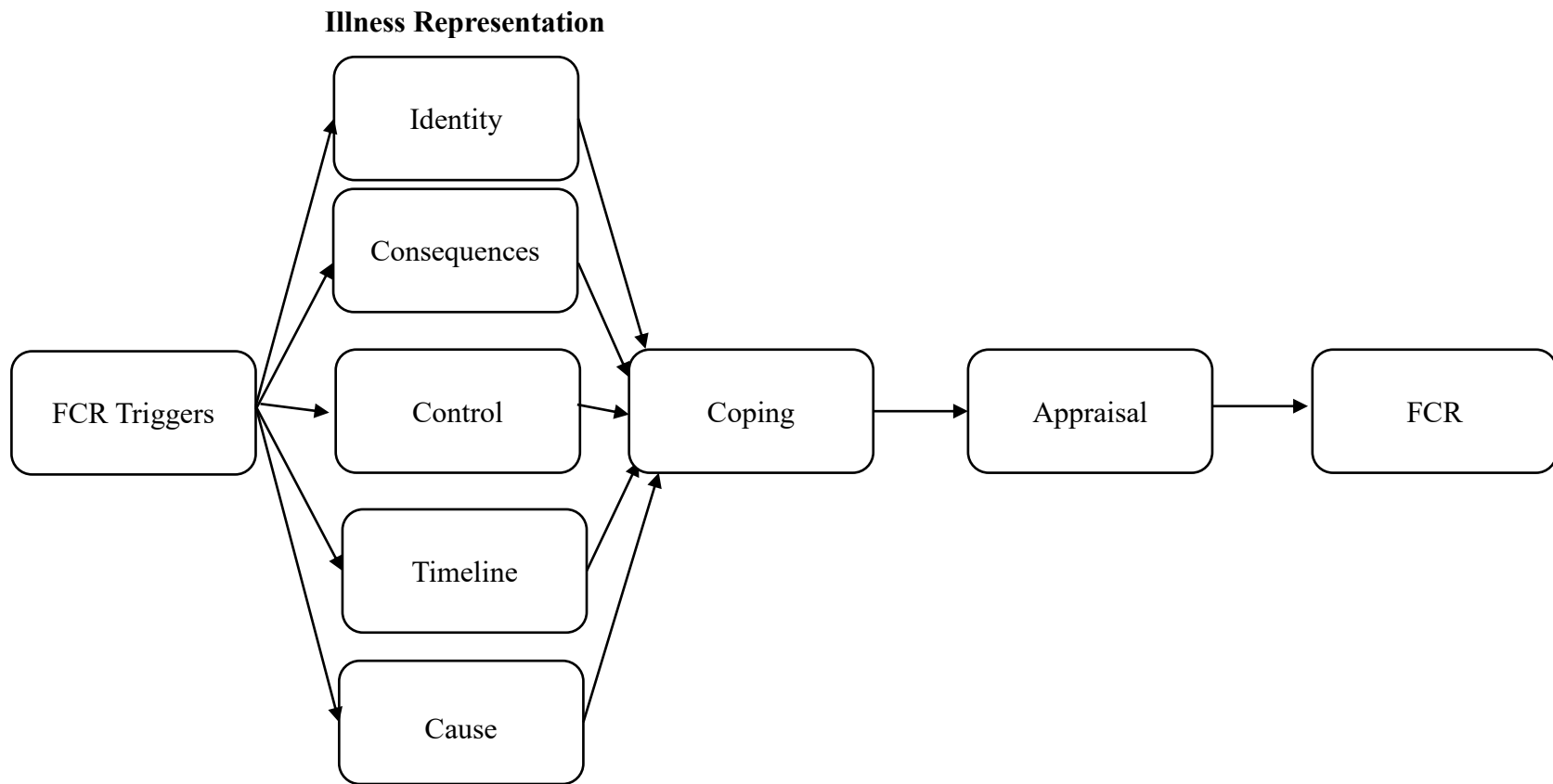


Figure 2: Theoretical Model of FCR based on the Leventhal Common-Sense Model (Lee-Jones et al. 1997)

Study 1: Untangling the Relationship Between Fear of Cancer Recurrence and Health

Behaviours: a Nationwide Longitudinal Study of Cancer Survivors

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Abstract

Objective: The goal of this study was to explore fear of cancer recurrence (FCR) and two health behaviours, physical activity and fruit and vegetable intake, from early to long-term survivorship in a large cohort of mixed cancer survivors. *Methods:* Group-based trajectory analyses and repeated measures analysis of variance were conducted on data collected in the American Cancer Society's Studies of Cancer Survivorship-I. Two thousand three hundred and thirty-seven survivors of ten cancers completed the survey at three time points ($M=1.3, 2.2$ and 8.8 years post-diagnosis). *Results:* The current study found three FCR trajectories clustering cancer survivors by FCR severity: low (33.6%), moderate (58.1%), and high (8.3%). FCR significantly decreased over time and remained distinct for each trajectory group. Patient characteristics prevalent in the high FCR group were being female, of younger age, Hispanic ethnicity, having advanced cancer stage (II-III) and Non-Hodgkin lymphoma, and low adherence to physical activity and fruit and vegetable intake recommendations. The high FCR group also reported significantly fewer of these health behaviours compared to the other groups albeit the effect size was small. *Conclusions:* Across the survivorship trajectory, FCR severity decreased but remained distinct for the three trajectory groups. Future investigations should inquire on the specific needs of each FCR group to subsequently develop targeted interventions. A weak association between FCR and health behaviours was found, with individuals in the high FCR group reporting less health behaviours. Future research should assess the direction of this relationship over time, to inform intervention targets within this sub-group.

Keywords: diet, fear of cancer recurrence, longitudinal, oncology, physical activity

Untangling the Relationship Between Fear of Cancer Recurrence and Health Behaviours: a Nationwide Longitudinal Study of Cancer Survivors

The fear of cancer recurrence (FCR) is recognized as one of the most common concerns among cancer survivors (Simard et al., 2013; Simonelli, Siegel, & Duffy, 2017). It is defined as the "fear, worry, or concern relating to the possibility that cancer will come back or progress" (Lebel et al., 2016). A seminal paper published by Lee-Jones et al. (1997) conceptualized FCR as a multidimensional construct that manifests itself in various ways, affecting cognitions, behaviours, and emotions. This theoretical FCR formulation stipulates that internal and external cues serve as illness threat reminders that influence illness representation. In turn, illness representation will predict perceived risk of cancer recurrence which subsequently influences two parallel processes: first, the psychological effects - the severity and impact of FCR and second, the behavioural responses - the coping mechanism used to manage FCR (Lee-Jones, Humphris, Dixon, & Bebbington Hatcher, 1997).

Prevalence of FCR

Thus far, the literature on FCR has mainly focused on the first process, working towards a definition of FCR, determining its severity and impact on cancer survivors, and establishing its prevalence (Crist & Grunfeld, 2013; Koch, Jansen, Brenner, & Arndt, 2013; Simard et al., 2013; Simonelli et al., 2017). From diagnosis to early survivorship (i.e. two years post active treatment, (Stanton, Rowland, & Ganz, 2015)) a wide-range of prevalence has been observed across studies: 15-76% of cancer patients with low FCR, 40-68% with moderate FCR and 9%-56% with high FCR (Halbach et al., 2016; Krok-Schoen, Naughton, Bernardo, Young, & Paskett, 2018; Mehnert, Koch, Sundermann, & Dinkel, 2013; Ratcliff, Naik, Martin, & Moye, 2017; Sarkar et al., 2014; Savard & Ivers, 2013). A clearer picture has emerged in studies looking at FCR

prevalence later in the cancer survivorship trajectory (5-8 years post diagnosis). These have observed 76-87% with low FCR, 9-15% with moderate FCR and 4-9% with high FCR (Koch et al., 2014; Koch-Gallenkamp et al., 2016; Mehnert et al., 2013). The following patient characteristics have consistently predicted higher FCR: younger age, being female, lower education, and Hispanic ethnicity (Crist & Grunfeld, 2013; Koch et al., 2013; Simard et al., 2013; Simonelli et al., 2017). For cancer stage and cancer site predicting FCR severity the evidence has been weaker (Koch-Gallenkamp et al., 2016; Savard & Ivers, 2013; van de Wal, van de Poll-Franse, Prins, & Gielissen, 2016).

Most studies reporting on FCR severity are limited by their use of cross-sectional designs. The few longitudinal studies currently available are limited to 2 years post-diagnosis and indicate that FCR is stable over time (Crist & Grunfeld, 2013; Koch et al., 2013; Simard et al., 2013; Simonelli et al., 2017), but other recent studies have found FCR severity to significantly decrease over time (Dunn et al., 2015; Halbach et al., 2016; Mehnert et al., 2013; Sarkar et al., 2014). These studies did not take into consideration distinct FCR trajectories within their samples which could explain the mixed findings. There is preliminary evidence that subgroups of cancer survivors follow distinct patterns of FCR changes over time depending on FCR severity (Melchior et al., 2013; Savard & Ivers, 2013). Indeed, two studies of survivors from diagnosis to 12-18 months post diagnosis found a greater decrease in FCR among higher FCR groups in comparison to low FCR groups (Melchior et al., 2013; Savard & Ivers, 2013). An additional limitation is that the majority of longitudinal FCR studies were conducted with one cancer site (predominantly breast), which limits generalizability across cancer sites. Given the inconsistent prevalence results and the limited longitudinal studies looking at FCR trajectories, additional analyses are needed to look at FCR trajectories from early to long-term survivorship,

across more than one disease site.

Behavioural Responses to FCR

Research on behavioural responses to FCR, the second process described by Lee-Jones, has mainly focused on specific coping behaviours such as reassurance seeking and body checking but little research has been conducted on other health-related behaviours. Cancer is commonly conceptualized as a "teachable moment", motivating cancer survivors to engage in healthy lifestyle behaviours (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005). Moreover, in Lee-Jones' model, FCR is conceptualized as a motivating factor promoting health behaviours. However, there is a lack of empirical evidence regarding the role of FCR on health behaviours. Shedding light on this relationship is crucial given evidence that the majority of cancer survivors do not adhere to recommended American Cancer Society (ACS) guidelines (Kushi et al., 2012) of at least 150 minutes of moderate physical activity or 75 minutes of vigorous physical activity weekly and the intake of at least five portions (5-a-day) of fruits and vegetables each day (Blanchard, Courneya, & Stein, 2008; Bluethmann et al., 2015; Brunet, Amireault, Chaiton, & Sabiston, 2014; Hawkins et al., 2017; LeMasters, Madhavan, Sambamoorthi, & Kurian, 2014).

To date, the few studies looking at the association between FCR and physical activity/dietary changes in cancer survivors report conflicting results (Fisher, Beeken, Heinrich, Williams, & Wardle, 2016). While some studies found no significant association between FCR and physical activity and diet (Alfano et al., 2009; Burris, Jacobsen, Loftus, & Andrykowski, 2012; Mosher et al., 2008), one study found a negative relationship, where higher FCR predicted less physical activity (Fisher et al., 2016) and two studies found a positive relationship, with higher FCR associated with greater engagement in physical activity and positive dietary changes (Hawkins et al., 2010; Maunsell, Drolet, Brisson, Robert, & Deschênes, 2002). Of these studies,

only one used a longitudinal design and found higher FCR to predict greater dietary changes from 3 days to 12 months post-diagnosis (Maunsell et al., 2002). Therefore, further investigation of the relationship between FCR and physical activity and diet beyond early survivorship is required (Bluethmann et al., 2015; Brunet et al., 2014).

Study Objectives.

Overall, this study aims to clarify the relationship between FCR and health behaviours (physical activity and fruit and vegetable intake) by using a longitudinal design of a population-based sample of survivors of ten cancers, from early to long-term survivorship.

- 1) The first objective was to identify distinct longitudinal FCR trajectories within the sample and to identify participant characteristics associated with each trajectory group.
- 2) The second objective was to explore the physical activity and fruit and vegetable intake reported by cancer survivors, first by comparing these behaviours between trajectory groups and over time, and second by establishing the rate of adherence to recommended health behaviours and comparing them by trajectory group.

The authors hypothesised that three distinct FCR trajectories: low, moderate, and high FCR would be identified. FCR was hypothesised to significantly decrease over time across all three trajectories but the higher FCR group was expected to show a greater reduction in FCR than the other groups. Patients with the following characteristics: younger age, female, Hispanic ethnicity, and high school education or less were expected to be more prevalent in the high FCR group. Given the weak evidence, no hypotheses were noted regarding cancer stage or cancer site between trajectory groups.

Despite mixed findings, based on theory (Demark-Wahnefried et al., 2005; Lee-Jones et

al., 1997) the high FCR group was expected to report more physical activity and fruit and vegetable intake than the moderate and low FCR groups. Moreover, as FCR decreases over time physical activity and fruit and vegetable intake was expected to also decrease across time in all three trajectory groups.

Methods

Procedure

The current study used data from the American Cancer Society's Study of Cancer Survivors-I (SCS-I), a national prospective longitudinal study of American cancer survivors. Questionnaire packages were administered in three waves beginning in 2000, T1, $M = 1.3$ years ($SD = 0.32$), T2, $M = 2.2$ years ($SD = 0.34$), and T3, $M = 8.8$ years ($SD = 0.63$) post cancer diagnosis. The questionnaire packages were slightly modified between administrations to include recent measurement tools, therefore not all questionnaires were available at all three time points. The purpose of the survey was to collect data to examine quality of life in American cancer survivors (Smith et al., 2007). Participants were recruited from 25 randomly selected cancer registries across the United States. Participant eligibility criteria were the following: diagnosed with one of the ten most highly incident cancers (prostate, breast, lung, colorectal, bladder, non-Hodgkin lymphoma (NHL), skin melanoma, kidney, ovarian, and uterine), over 18 years old at diagnosis, residing in one of the target states at the time of diagnosis, and diagnosed with a local, regional, or distant SEER Summary Stage cancer. Survivors were ineligible for the study if they were unable to complete the survey due to mental incompetence, unable to communicate in English or Spanish, or had terminal illness (Smith et al., 2007). The studies were approved by the Institutional Review Board of Emory University (Atlanta, GA), for each state, including the Connecticut Department of Public Health Human Investigation Committee, and the University of

Ottawa Research and Ethics Board (Ottawa, Ontario). Additional details on recruitment and methodology are available elsewhere (Smith et al., 2007).

Measures

Socio-demographic and medical characteristics. The following socio-demographic and medical variables were considered as potential covariates for the study based on prior empirical evidence of possible association with FCR (Crist & Grunfeld, 2013; Simard et al., 2013; Simonelli et al., 2017): age at diagnosis, sex, ethnicity, education, cancer site, and cancer stage. Age at diagnosis, sex, ethnicity, and education were self-reported by participants at time 1. Time since cancer diagnosis, cancer site and cancer stage were self-reported and cross-validated using cancer registries. Education was dichotomized to high school or less and college or more, and cancer stage was dichotomized to stage 0-I and II-III. Additionally, relationship status, family income and occupation were included for sample description purposes. To assure systematic reporting of sex in research, data will be disaggregated by sex following the SAGER guidelines (Heidari et al. 2016).

Cancer Problems in Living Scales (CIPLS). FCR was assessed at all three time points with the Cancer Problems in Living Scales (CIPLS)-FCR subscale (Baker, Denniston, Zabora, & Marcellus, 2003). Using a three-point Likert scale, respondents indicated how much of a problem each item was in the last 12 months: feeling fearful that my illness will return, concern about my cancer relapsing, fears about the future, and preoccupation with being ill. Item scores were added to determine FCR severity, with a possible range of 0-12. The CIPLS- FCR subscale has good internal consistency with a Cronbach's alpha of 0.79-0.84 (Zhao, Portier, Stein, Baker, & Smith, 2009; Zhao et al., 2007) and good discriminant validity with other psychological scales, including the SF-36 mental health composite score ($r = -0.11$), the Profile of Mood States ($r =$

0.10), and the Rotterdam Symptoms Checklist- Modified ($r = 0.12$) (Thewes et al., 2012).

According to a systematic review of FCR measures (Thewes et al., 2012), it is an appropriate tool for large cohort studies such as the SCS-I.

The 9-item Fear of Cancer Recurrence Inventory -Severity subscale (FCRI-s), considered the gold standard measure of FCR (Simard & Savard, 2009; Thewes et al., 2012), was administered at time 3 to cross-validate FCR severities. FCRI-s scores were computed for each trajectory group to allow for a meaningful interpretation and facilitate comparison with previous studies. The subscale score which ranges from 0 to 32, has good internal consistency ($\alpha = 0.89$) and good test-retest reliability after one month ($r = 0.80$) (Simard & Savard, 2009). The initial cut-off score for clinical FCR was found to be 13 (Simard & Savard, 2009) although additional studies suggested cut-off scores of 16 and 22 (Fardell et al., 2018).

Leisure-Time Exercise Questionnaire (LTEQ). The Leisure-Time Exercise Questionnaire (LTEQ) was used in this study to assess physical activity at time 2 and time 3. Respondents indicated the number of minutes they spent engaging in mild, moderate, and vigorous physical activity in a typical week (Godin & Shepard, 1985). In this study, the LTEQ was administered at time 2 and time 3. The scale has shown good a test-retest reliability after two weeks ($r = 0.74$) and good convergent validity with maximum oxygen intake ($r = 0.83$) and values of body fat ($r = 0.85$) (Godin & Shepard, 1985). For the analysis, the total number of minutes spent engaging in moderate and vigorous physical activity weekly was computed (Kushi et al., 2012). The percentage of respondents reporting ≥ 150 minutes of moderate or ≥ 75 minutes of vigorous physical activity per week was computed to determine the rate of adherence to the ACS guideline.

Five-A-Day. The 5-A-Day measure is a one item scale developed by the ACS to measure

adherence to the recommended five servings of fruits and vegetables a day (Smith et al., 2007). Respondents indicated in a typical week in the past month, how many days per week they consumed the five daily servings of fruits and vegetables. In this study, the 5-a-day was administered at time 2 and time 3. To determine the rate of adherence to the ACS guideline, the percentage of respondents meeting the 5-a-day 7 days a week criteria was calculated.

Data Analysis Strategy

Data was screened and cleaned using SPSS. Participants who completed the CIPLS-FCR in its entirety at all three times points were retained for analysis (N= 2,337). Expectation-maximization imputation method was used to impute the 3% of missing data (Dong & Peng, 2013). Associations between potential covariates and outcome variables were calculated using Pearson correlations. Significant covariates were included in subsequent analyses.

Establishing FCR trajectories. Using the TRAJ procedure in SAS, group-based trajectory analyses were conducted to identify distinct subgroups of individuals following a similar FCR progression (Jones, Nagin, & Roeder, 2001). This technique uses a finite mixture model to cluster participants based on their progression over time. Given that the dependent variable is continuous, the censored normal distribution was selected to estimate model parameters. To identify the FCR trajectories that best describe the data, several models were tested to optimize the number of groups, the trajectory parameters, and the overall model fit using the Bayesian information criterion (BIC) and the Akaike information criterion (AIC) fit indices. To formally compare model fit indices, the log Bayes factor was computed, where a factor ≥ 10 was strong evidence that the complex model best described the data (Jones et al., 2001). Once the trajectories were identified, the potential covariates, known as risk factors, were added to the model. As a final verification, the mean posterior probabilities were calculated for

each trajectory group, where a mean > 0.80 confirmed the model adequacy (Nagin, 2005).

Trajectory group analyses. Repeated measures analysis of variance (ANOVA) was conducted to measure FCR changes over time that assessed interaction, time and group effects. One-way ANOVA and chi-squares compared participant characteristics between trajectory groups. For physical activity and fruit and vegetable intake repeated measures ANOVA assessed interaction, time, and group trajectory effects. Prevalence of adherence to the ACS health behaviour guidelines was established by determining the proportion of patients who met the physical activity and the 5-a-day fruits and vegetables recommendations within this sample. Subsequently, chi-square tests were conducted to compare adherence by trajectory group.

Post-hoc and effect size analyses. For each of the previously mentioned analyses, post-hoc tests and effect sizes were computed to further assess significant results. For the ANOVAs, post-hoc Tukey tests at a level of significance greater than 0.05 and pairwise comparisons with a corrected Bonferroni alpha were calculated to specify the occurrence of significant differences. Likewise, the adjusted standardized residuals at a level of significance greater than 0.01, $z = 2.58$ were obtained to locate significant group differences detected in chi-square analyses. To estimate the extent of group differences, effect sizes (partial η^2 for ANOVAs and ϕ for chi-squares) were obtained in SPSS. The Cohen's guidelines to interpret magnitude of effect were used, where effect size is small if $\eta^2 = 0.01$ or $\phi = 0.1$, medium if $\eta^2 = 0.06$ $\phi = 0.3$, and large if $\eta^2 = 0.14$ or $\phi = 0.5$ (Cohen, 1992).

Results

Study Sample

The 2,337 participants in the sample were mostly Caucasian (90%), female (60%), with a college education or higher (68%), and with a mean age of 56 at diagnosis. The most common

cancer sites were breast (29%), prostate (21%), and colorectal (14%). See table 1 for all participant socio-demographic and medical characteristics.

FCR Covariates

Among the potential covariates, age at diagnosis, sex, ethnicity, cancer stage, breast, prostate, NHL, lung and ovarian cancer sites were significantly correlated with FCR at the three time points and thus were included in the Proc Traj analyses. Education and the other cancer sites were not significantly correlated with FCR and therefore excluded from the model analyses.

Establishing the FCR trajectory groups

The three-group model best described the trajectories within the sample given the combination of significant model parameters, lowest BIC and AIC, and a log Bayes factor ≥ 10 , $2\Delta\text{BIC} = 600$ (Table 2). Risk factors were systematically added to the three-group model but only age at diagnosis and sex improved model fit and had predictive effects on the probability of belonging to a trajectory group. Specifically, being younger, $\beta_1 = -0.06$, $p < .001$; $\beta_2 = -0.11$, $p < .001$, and female, $\beta_1 = 0.57$, $p < .001$; $\beta_2 = 0.81$, $p < .001$, predicted higher FCR severity. The average posterior probabilities for each trajectory in the final model with age at diagnosis and sex, were greater than .80; trajectory 1 ($M = 0.92$, $SD = 0.12$), trajectory 2 ($M = 0.93$, $SD = 0.12$) and trajectory 3 ($M = 0.88$, $SD = 0.14$). Thus, three distinct FCR trajectories were identified in the sample (Figure 1).

FCR progression by trajectory group. Trajectory 1 described cancer survivors with low FCR ($n = 786$, 34%). The trajectory followed a quadratic trend in which FCR severity decreased between time 1 and time 2 and slightly increased at time 3, $\beta_0 = 0.42$, $p = .11$; $\beta_1 = -0.07$, $p < .001$; $\beta_2 = 0.001$, $p < .001$. Trajectory 2 represented most of the sample ($n = 1,357$, 58%); these participants reported moderate FCR severity. This trajectory followed a linear

decrease of FCR severity from time 1 through time 3, $\beta_0 = 4.74, p < .001$; $\beta_1 = -0.02, p < .001$. Finally, trajectory 3 characterized participants with high FCR severity ($n = 194, 8\%$). The trajectory followed a quadratic trend where FCR severity followed a steep decrease between Time 1 and Time 2 and continued to decrease more gradually between time 2 and time 3, $\beta_0 = 10.07, p < .001$; $\beta_1 = -0.08, p = .001$; $\beta_2 = 0.0004, p = .009$.

The evolution of FCR severity yielded a significant group x time interaction, $F_{(4, 2334)} = 107.45, p < .001$, partial $\eta^2 = .084$. Multivariate simple effects of time within each FCR group with a corrected Bonferroni alpha ($\alpha = 0.017$) yielded a significant effect for all three groups. Simple effects of FCR groups showed that although there was a significant decrease in FCR over time, the magnitude of change for the low FCR group was small, $F_{(2, 785)} = 27.25, p < .001$, partial $\eta^2 = .034$, but was large for the moderate, $F_{(2, 1356)} = 499.28, p < .001$, partial $\eta^2 = .269$, and high FCR groups, $F_{(2, 193)} = 67.7, p < .001$, partial $\eta^2 = .260$. Pairwise comparisons with a corrected Bonferroni alpha ($\alpha = 0.005$) showed significant difference in FCR severity between all three time points within the moderate and high FCR groups, and for the low FCR group, FCR at time 1 was significantly different than time 2 and time 3 but there was no significant difference between time 2 and 3. At time 3, the mean FCRI-s scores for each trajectory group were computed to cross-check FCR severity; low FCR group ($M = 6.52, SD = 4.77$), moderate FCR group ($M = 12.77, SD = 6.02$) and high FCR group ($M = 21.36, SD = 6.89$).

Patient characteristics by trajectory group. ANOVA and chi-squares indicated significant differences between trajectory groups for age at diagnosis, $F_{(2, 2334)} = 163.06, p < .001$, $\eta^2 = .123$; sex $\chi^2 = 92.99, p < .001, \phi = .199$, ethnicity, $\chi^2 = 36.54, p < .001, \phi = .125$; cancer type $\chi^2 = 155.08, p < .001; \phi = .258$, and cancer stage $\chi^2 = 42.76, p < .001, \phi = .135$, but not education

(Table 3, supplemental material). Post-hoc Tukey tests revealed that cancer survivors who were younger at diagnosis were more likely to be in the high FCR group ($M = 48.7$) compared to the moderate ($M = 54.4$) and low ($M = 61.3$) FCR groups.

Chi-square analyses indicated that, compared to the proportion of females, the proportion of males was higher in the low FCR group (53%), but lower in the moderate and high FCR groups (34% and 25%, respectively). The proportion of Hispanic survivors in the high FCR group (9%) was greater than the low and moderate FCR groups (3% and 2%, respectively). Meanwhile, Caucasian survivors were more prominent in the low and moderate FCR groups (91%, for both) in comparison to the high FCR group (81%). The largest proportion of survivors in the low FCR group were diagnosed with prostate cancer (33%), but their proportion in the moderate FCR groups was lower (16%), and was lowest in the high FCR group (6%). In contrast, the proportion diagnosed with breast cancer in the low FCR group (23.5%) was lower than the moderate and high FCR groups (31.2% and 30.9%, respectively). The proportion diagnosed with NHL in the low FCR group was 4.1%, but the proportion was higher in the moderate FCR group (7%), and highest in the high FCR group (12%). Ovarian cancer survivors constituted 2% of survivors in the low FCR group, but their proportions were higher in the moderate and high FCR groups (5% and 7%, respectively). In terms of cancer stage, the proportion of participants with early stage cancer was highest in the low FCR group (77%), but lower in the moderate and high FCR groups (70% and 54%, respectively). See table 4 for data disaggregated by sex.

Physical activity by trajectory group

In the total sample, participants reported engaging in 105.70 (SD = 159.25) and 97.59 (SD = 151.28) minutes of moderate to vigorous physical activity per week at time 2 and time 3

respectively. The evolution of physical activity yielded a non-significant group x time interaction, $F_{(2, 2334)} = 0.25, p > .05$. There was no time effect, $F_{(1, 2334)} = 3.07, p = .08$ but a significant group effect was found, $F_{(2, 2334)} = 4.46, p = .012$ partial $\eta^2 = .004$. Post-hoc Tukey test revealed that survivors in the high FCR group engaged in significantly less physical activity than the other groups at both time points (T2 $M = 80.47$, T3 $M = 72.45$). In the total sample, 28% (at time 2) and 25% (at time 3) of participants met the suggested 75 minutes of vigorous physical activity or 150 minutes of moderate to vigorous physical activity per week. The proportion of participants who met the physical activity guidelines did not differ by FCR trajectory group at time 2, $\chi^2 = 4.57, p > .05$ or time 3, $\chi^2 = 3.74, p > .05$.

Fruit and vegetable intake by trajectory group

The average number of days participants consumed 5 servings of fruits and vegetables per week was 3.80 days ($SD = 2.32$) and 3.31 days ($SD = 2.17$) at time 2 and 3 respectively. The evolution of fruit and vegetable intake yielded a non-significant group x time interaction $F_{(2, 2334)} = 0.876, p > .05$. There was a significant time $F_{(1, 2334)} = 65.75, p < .001$, partial $\eta^2 = .027$ and group effect $F_{(2, 2334)} = 5.93, p = .005$, partial $\eta^2 = .005$. Post-hoc Tukey test revealed that the high FCR group (T2 $M = 3.44$, T3 $M = 2.78$) had a lower 5-a-day score compared with the low and moderate FCR groups at both time points. In terms of adherence to ACS recommendations, 18% at time 2 and 11% at time 3 of survivors met the recommended 5-a-day. At time 2, the proportion of survivors who met the 5-a-day did not differ by FCR trajectory group, $\chi^2 = 5.19, p > .05$. However, at time 3 a difference was observed, $\chi^2 = 6.77, p = 0.034, \phi = 0.054$; the low FCR group was more likely to meet the 5-a-day than the moderate and high FCR groups.

Discussion

The goal of the current study was to explore FCR, physical activity and fruit and

vegetable intake from early to long-term survivorship in a large cohort of mixed cancer survivors. To adequately capture the evolution of FCR amongst cancer survivors, distinct FCR trajectories were established and used to explore the health behaviours.

FCR Severity Groups

As hypothesized, our data observed three distinct clusters of FCR severity: low, moderate, and high. While other studies have also classified participants in three FCR severity groups using scale cut-offs, the FCR groups were established using statistical methods clustering participants based on their FCR progression in time, strengthening the evidence of distinct FCR groups and highlighting the continuity of these profiles in the survivorship trajectory.

In this sample, most cancer survivors were in the moderate FCR group, followed by the low FCR group, and finally the high FCR group. In comparison with early survivorship studies (within 2 years post diagnosis), the proportion of cancer survivors experiencing high FCR was lower in this sample (Halbach et al., 2016; Krok-Schoen et al., 2018; Mehnert et al., 2013; Ratcliff et al., 2017; Sarkar et al., 2014; Savard & Ivers, 2013). However, findings were similar to studies assessing FCR severity in long term survivors (Koch et al., 2014; Koch-Gallenkamp et al., 2016; Mehnert et al., 2013) among whom there is a downward trend in FCR over time. Moreover, given that all three time points were considered when clustering individuals by FCR severity, there was likely an under-representation of high FCR prevalence at individual time points. Another explanation for these mixed findings is the heterogeneity in FCR measurement tools.

Our results underline the challenges of measuring FCR severity and indicates that current scale cut-offs may be inflating the number of cancer survivors labelled as having high FCR. The FCRI-s score for the high FCR group at time 3 was 21.36 which is much greater than the

recommended clinical cut-off of 13 on the FCRI-s. Moreover, in this sample survivors in the moderate FCR group had a mean score of 13 on the FCRI-s. As suggested by Fardel et al. (2018), a cut-off of 22 would be a more accurate indicator of high FCR severity in this sample.

In accordance with our hypothesis, FCR significantly decreased from early to long-term survivorship. The study findings do not support the provisional conclusion that FCR is stable over time (Crist & Grunfeld, 2013; Koch et al., 2013; Simard et al., 2013; Simonelli et al., 2017). However, this conclusion was drawn from studies limited by their cross-sectional design and their narrow sample of disease sites. In contrast, the current study used a larger sample size of survivors of ten cancers who were assessed longitudinally.

Our results also corroborated recent longitudinal studies that found FCR to significantly decrease over time (Dunn et al., 2015; Halbach et al., 2016; Mehnert et al., 2013; Sarkar et al., 2014). Similar to the approach used in this study, two studies distinguished between FCR profiles to assess FCR progression and found that the high FCR groups showed a greater decrease in FCR severity (Melchior et al., 2013; Savard & Ivers, 2013). The current study observed significant decreases in FCR for all trajectory groups, but the magnitude of change was greater for the high and moderate FCR groups in comparison to the low FCR groups. Given that the previous longitudinal studies were limited to early survivorship, this study extends past findings from short to long-term survivorship. These results highlight the importance of distinguishing between FCR sub-groups, as these groups follow a different progression in time and remain distinct across the survivorship trajectory. Moreover, cancer survivors' characteristics differed by trajectory group.

Cancer Survivor Characteristics by FCR Severity Groups

In accordance with previous studies, survivors with the following characteristics were

more prevalent in the high FCR group: female sex, younger age at diagnosis, and Hispanic ethnicity (Crist & Grunfeld, 2013; Koch et al., 2013; Simard et al., 2013; Simonelli et al., 2017). Results regarding ethnicity should be interpreted with caution given the small representation of non-Caucasians in this sample. Contrary to the author's hypothesis, education levels did not significantly differ between groups. Despite mixed findings in the literature, cancer stage and cancer site were found to significantly differ between groups; in the high FCR group, the proportion of survivors diagnosed with advanced cancer stage and with NHL cancer was higher compared to their proportions in the low and moderate FCR groups. In addition, the proportion of participants with prostate cancer was highest in the low FCR group, whereas the proportion of breast and ovarian cancer survivors was highest in the moderate and high FCR groups. These results could be related to sex, given the sex specificity of cancer sites. Moreover, by segregating data by sex, significant group differences were found across outcomes (including FCR and health behaviours) indicating that male and female cancer survivors differ. Therefore sex differences should be considered in FCR research. Establishing the empirical evidence of the relationship between patient characteristics and FCR severity is clinically useful, as it can improve screening tools to assess FCR severity in cancer patients.

Physical Activity and Diet by FCR Severity Groups

Overall, only a minority of cancer survivors adhered to the recommended health behaviours. In this sample, 25% and 28% of cancer survivors at time 2 and time 3, respectively, met the physical activity guidelines which was within the range (14-49%) reported in previous cancer survivor studies (Blanchard et al., 2008; Bluethmann et al., 2015; Brunet et al., 2014; Hawkins et al., 2017; LeMasters et al., 2014). Even fewer, 11% and 18% at time 2 and time 3 met the 5-a-day fruit and vegetable guideline, which was in the lower range (14-51%) observed

in previous studies (Blanchard et al., 2008; Bluethmann et al., 2015; LeMasters et al., 2014). Cancer survivors who met the recommended physical activity and fruit and vegetable intake did not differ by FCR group except at time 3, where the 5-a-day adherence rate was greater in the low FCR group than in the moderate and high FCR groups. Overall, FCR severity was not associated with increased adherence to health behaviours.

In general, participants in the high FCR group reported less physical activity and less fruit and vegetable intake than the moderate and low FCR groups. Although the group effect was significant, the effect size was small. These findings do not support the "teachable moment" theory or the Lee-Jones' theory suggesting that cancer survivors who experience greater FCR are motivated to engage in health behaviours (Demark-Wahnefried et al., 2005; Lee-Jones et al., 1997). It is possible that FCR severity may neither encourage nor hinder most cancer survivors to engage in these health behaviours. However, there is emerging evidence that a small portion of cancer survivors with high FCR engage less in health behaviours. As suggested in previous studies, cancer survivors in the high FCR group might be experiencing high levels of distress and preoccupations that impact their ability to function, including adhering to healthy lifestyle recommendations (Mutsaers et al., 2016).

Clinical Implications

Although FCR severity reduced over time, a sub-group of cancer survivors persistently experienced high levels of FCR across the survivorship trajectory. These cancer survivors tend to be younger, female, of Hispanic ethnicity, diagnosed with advanced cancer stage and with NHL. Moreover, in the largest subgroup, cancer survivors who tend to be women diagnosed with breast or ovarian cancers and who are slightly younger than the high FCR group, persistently experience moderate levels of FCR across time. Interestingly, there is a proportion of cancer

survivors who report low or no FCR across time; these cancer survivors tend to be older, male, diagnosed with early cancer stage, and with prostate cancer.

While there is strong empirical evidence of FCR sub-groups, the FCR severity indicative of clinical levels remains unknown. This highlights the need to better define the features of clinical FCR to adequately screen for FCR in cancer patients (Maheu & Galica, 2018).

As suggested in the literature, cancer survivors' needs might differ by FCR group and therefore interventions should be tailored for each group (Ratcliff et al., 2017). Current FCR interventions target patients with high FCR severity, who generally qualify for therapy if their FCRI-s score is greater than 13 but pre-intervention scores tend to be closer to 22 (Butow et al., 2017; Lebel et al., 2014; van de Wal, Thewes, Gielissen, Speckens, & Prins, 2017). Literature on the intervention needs of moderate and low FCR groups remains sparse. Future investigations should examine the needs of the low and moderate FCR groups to determine what, if any, interventions should be developed to help those cancer survivors.

The association between FCR and physical activity/diet was weak. Perhaps the link between health behaviours and reduction of recurrence risk (and thus possibly of lower FCR) was not obvious to cancer survivors in the present study. Therefore, these results call into question the relevance of considering health behaviours when addressing clinical FCR. Yet, the emerging trend of cancer survivors with high FCR engaging less in health behaviours found in this study and past studies (Fisher et al., 2016) warrants further investigation. Future studies should aim to establish the direction of this relationship over time for individuals with high FCR. Although health behaviour recommendations for cancer survivors have been published for over 15 years, adherence remains relatively low. Beyond FCR, engaging in a healthy lifestyle is an important indicator of overall health and wellbeing in cancer survivors (Kushi et al., 2012).

Therefore, further investigations are needed to identify the predictive factors of health behaviour adherence in the overall cancer survivor population.

Study Limitations

While this study had strengths such as a large cohort of mixed cancer survivors and a longitudinal design spanning from early to long term survivorship, the study had some limitations. Firstly, although the ACS has developed a protocol to obtain an optimal sample of American cancer survivors, individuals who completed the questionnaire packages have specific characteristics, such as being female and higher education (Smith et al., 2007). Secondly, only a sub-sample of participants completed all three SCS-I questionnaire packages limiting this sample and creating a less diverse cohort of survivors.

All measures used in this study are self-report questionnaires. Therefore, data is susceptible to the respondent's ability to recall and social desirability. This is particularly true for the measures of physical activity and fruit and vegetable intake as these health behaviours were not objectively observed and relied on participant's subjective measure of their habits. Despite this, the LTEQ and the 5-a-day measures have been shown to be reliable indicators of health behaviours (Smith et al., 2007). Furthermore, data collection began in the early 2000's and health behaviours, particularly physical activity, were only formally recommended starting in 2003 (Kushi et al., 2012). Therefore, uptake of these behaviours in response to recommendations may be delayed. Nevertheless, there was no significant change in physical activity at time 3 although the guidelines had been published for several years. Moreover, adherence rates for physical activity and fruit and vegetable intake in this sample were similar to rates measured in the last few years (Bluethmann et al., 2015; Brunet et al., 2014; Hawkins et al., 2017; LeMasters et al., 2014).

Conclusion

FCR decreased over time from early to long term survivorship, and FCR severity continuously showed three distinct trajectory groups, low, moderate and high. Future research should identify the specific needs of each trajectory group and develop appropriate evidence-base interventions. In the overall sample, a modest relationship between FCR severity and physical activity/fruit and vegetable intake was found. There is emerging evidence that cancer survivors with high FCR engage less in health behaviours. Further investigation is required to determine the direction of this relationship over time which could inform intervention targets for cancer survivors with high FCR.

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Study 1 Tables

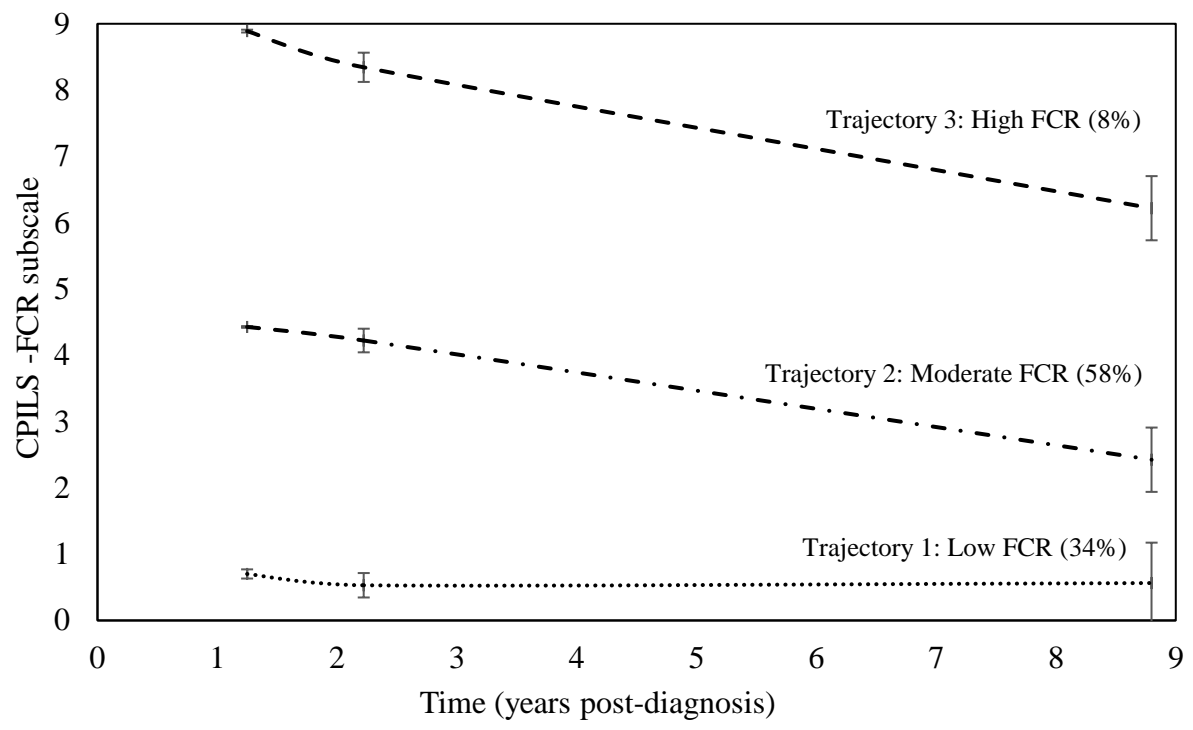


Figure 1. The fear of cancer recurrence (FCR) progression over time by trajectory groups. CPILS, Cancer Problems in Living Scale.

Table 1
Participant Characteristics, N = 2, 337

Variable	<i>M</i>	<i>SD</i>
Age at diagnosis (years)	56.22	11.19
Time since diagnosis (years)		
Time 1	1.3	0.32
Time 2	2.2	0.34
Time 3	8.8	0.63
	<i>n</i>	<i>%</i>
Sex		
Male	936	39.6
Female	1411	60.4
Ethnicity		
Caucasian	2100	89.9
African American	116	5
Hispanic	66	2.8
Other	45	1.9
Not indicated/missing	10	0.4
Education		
Highschool or less	727	31.1
College or more	1588	68
Not indicated/missing	22	0.9
Cancer Type		
Breast	668	28.6
Prostate	490	21
Colorectal	317	13.6
Uterine	152	6.5
NHL	152	6.5
Melanoma	139	5.9
Kidney	127	5.4
Lung	103	4.4
Ovarian	100	4.3
Bladder	89	3.8
Cancer Stage		
Stage 0 – 1	1649	70.6
Stage 2- 3	688	29.4
Civil Status		
Married/Cohabiting	1813	77.6
Divorced/Separated	226	9.7
Widowed	145	6.2
Single	145	6.2
Not indicated/missing	8	0.3
Household Income		
0-9,999	57	2.4
10,000-19,999	144	6.2
20,000-39,999	456	19.5
40,000-74,999	749	32
75,000 or more	641	27.4
Not indicated/missing	290	12.4
Occupation		
Employed full-time	1127	48.2
Employed part-time	196	8.4
Retired	577	24.7
Homemaker	148	6.3
Leave or Unemployed due to illness	119	5.1
Unemployed	73	3.1
Student	9	0.4
Not indicated/missing	88	3.8

Note. NHL, Non-Hodgkin lymphoma

Table 2
Model selection for FCR trajectory groups

Number of groups	Risk factors	BIC	AIC	2ΔBIC	Estimated probabilities (%)			
					1	2	3	4
1	-	-15,434.68	-15,423.17	-	100			
2	-	-14,550.59	-14,527.56	1768.18	38.9	61.1		
3	-	-14,250.90	-14,219.24	599.38	32.6	58.9	8.5	
4	-	-14,149.79	-14,103.74	202.22	15	31.6	46.9	6.5
3	sex & age	-14,123.35	-14,080.18	52.88	32.6	58.9	8.5	

Note. BIC, Bayesian information criterion; AIC, Akaike information criterion

Table 4
Participant characteristics and outcomes disaggregated by sex

Characteristic	Sex		ANOVA	
	Male	Female		
	<i>M (SD)</i>			
Age at diagnosis	59.21 (10.64)	54.26 (11.11)		
	<i>n (%)</i>			
Ethnicity				
Caucasian	842 (90.9)	1268 (89.9)		
African American	41 (4.4)	75 (5.3)		
Hispanic	25 (2.7)	41 (2.9)		
Other	18 (1.9)	27 (1.9)		
Education				
Highschool or less	293 (31.6)	438 (31)		
College or more	633 (68.4)	973 (69)		
Cancer Type				
Breast	1 (0.1)	667 (47.3)		
Prostate	490 (52.9)	0		
Colorectal	131 (14.1)	186 (13.2)		
Uterine	0	152 (10.8)		
NHL	72 (7.8)	80 (5.7)		
Melanoma	62 (6.7)	77 (5.5)		
Kidney	66 (7.1)	61 (4.3)		
Lung	41 (4.4)	62 (4.4)		
Ovarian	0	100 (7.1)		
Bladder	63 (6.8)	26 (1.8)		
Cancer Stage				
Stage 0-1	702 (75.8)	947 (67.1)		
Stage 2-3	224 (24.2)	464 (32.9)		
Outcomes	<i>M (SD)</i>		F	<i>p</i>
FCR (CIPLS-FCR)				
Time 1	3.09 (2.82)	4.14 (2.99)	72.20	< .001
Time 2	2.66 (2.63)	3.55 (2.85)	58.78	< .001
Time 3	1.82 (2.15)	2.44 (2.47)	39.69	< .001
MVPA				
Time 2	124.69 (184.44)	93.24 (138.95)	22.01	< .001
Time 3	118.35 (181.18)	83.97 (126.14)	29.23	< .001
5-a-Day fruit and vegetable				
Time 2	3.36 (2.37)	4.08 (2.23)	55.16	< .001
Time 3	3.02 (2.14)	3.51 (2.16)	28.89	< .001

Note. NHL, Non-Hodgkin lymphoma,

**Study 2: Can Physical Activity and Healthy Diet Help Cancer Survivors Manage their Fear
of Cancer Recurrence?**

Caroline Séguin Leclair, Dr. Sophie Lebel

Abstract

Objective: Fear of cancer recurrence (FCR) is detrimental to cancer survivors' mental health and quality of life. Survivors may use health behaviours to manage FCR but there is limited research investigating this relationship. Using the Common-Sense Model's (CSM) theoretical framework, this cross-sectional study examined the relationship between FCR and health behaviours (physical activity and fruit and vegetable intake) across three FCR severity groups (low, moderate and high). *Methods:* Path analyses were conducted on 2337 survivors ($M = 8$ years post diagnosis) of 10 cancers from the American Cancer Society Study of Cancer Survivorship-I. *Results:* Overall, results of good-fitting models indicated that engaging in physical activity or consuming fruits and vegetables did not influence FCR in most cancer survivors. Yet, this relationship was weakly significant in the low FCR group, where survivors reporting more health behaviours had a greater self-efficacy to manage health, which predicted lower FCR severity. In the low and moderate FCR groups, control over health and self-efficacy to manage health were strongly related to health behaviours. Meanwhile, in the high FCR group, these same variables were instead related to FCR. *Conclusions:* Although, the practice of health behaviours was not an adaptive response to manage FCR for most cancer survivors, the study results suggest it is a problem-focused response to manage illness outcomes. Further investigations are required to assess cancer survivors' perceived usefulness of health behaviours to manage the risk of cancer recurrence.

Keywords: Common-Sense Model, diet, fear of cancer recurrence, health behaviours, path analysis, physical activity

Can Physical Activity and Healthy Diet Help Cancer Survivors Manage their Fear of Cancer Recurrence?

The population of cancer survivors is persistently growing in North America (American Cancer Society, 2016). After cancer treatment, cancer survivors are left facing several psychosocial challenges, including fear of cancer recurrence (FCR) (Simard et al., 2013; Simonelli, Siegel, & Duffy, 2017). FCR is defined as the fear, worry, or concern relating to the possibility that cancer will come back or progress (Lebel et al., 2016). FCR is a multidimensional construct that manifests itself in different ways, affecting cognitions, behaviours, and emotions (Lee-Jones, Humphris, Dixon, & Bebbington Hatcher, 1997; Simard et al., 2013). Thus far, FCR research has mainly focused on identifying unhelpful coping responses to FCR (i.e. reassurance seeking, body checking, and avoidance) which contribute to the maintenance of cancer survivors' distress. Helpful coping responses to manage FCR, however, remain understudied. To better equip cancer survivors to manage FCR, identifying empirically supported adaptive coping responses is imperative.

With the growing body of evidence demonstrating that lifestyle changes have a countering effect on cancer progression/recurrence and promote healthy survivorship (Pekmezi & Demark-Wahnefried, 2011), cancer survivors are encouraged by health care practitioners to engage in health behaviours (i.e. physical activity and healthy diet). Specifically, the American Cancer Society recommends that cancer survivors engage in 150 minutes of moderate physical activity or 75 minutes of vigorous physical activity weekly and the intake of at least five portions (5-a-day) of fruits and vegetables each day (Kushi et al., 2012). Although, cancer is commonly conceptualized as a "teachable moment", motivating cancer survivors to engage in health behaviours (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005), most cancer survivors do not

adhere to these health behaviour guidelines (Bluethmann et al., 2015; Hawkins et al., 2017).

It is well established that health behaviours can help reduce the risk of cancer recurrence in survivors, but little is known of their relationship with FCR. Specifically, can engaging in health behaviours help survivors manage their FCR? Investigating the relationship between FCR and health behaviours is the first step to explore the hypothesized use of health behaviours as an adaptive coping response to manage FCR. To examine this relationship, Leventhal's Common-Sense Model (CSM) will be used as a theoretical guide.

Conceptualizing FCR using the Common-Sense Model

The CSM is the most comprehensive and evidenced-based theoretical approach applied to FCR (Fardell et al., 2016). Originally developed to encompass the cognitive, behavioural, and emotional responses to various illnesses (Leventhal, Diefenbach, & Leventhal, 1992), Lee-Jones et al, 1997, applied the CSM components to the cancer specific context, in their FCR theoretical formulation. The CSM components have since been empirically validated in cancer survivors (Fardell et al., 2016; Simonelli et al., 2017). According to this theoretical formulation, when an *illness threat* (triggers, i.e. aches and pains) is perceived, it activates the cancer survivor's *illness representation* informing the selection of *coping* response. Following the implementation of the coping response, the cancer survivor will assess if the coping strategy was effective (*appraisal*), thus influencing the illness and emotional *outcomes*, including FCR (Lee-Jones, Humphris, Dixon, & Bebbington Hatcher, 1997, Leventhal et al., 1992).

The illness representation is comprised of five illness attributes; *illness identity* – refers to the illness label (cancer) and related symptoms (e.g. fatigue), *consequences* – refers to the perceived impact of cancer on an individual's life, including social, psychological and physical consequences (e.g., impact on family), *control* – refers to the perceived level of control over

cancer or curability by oneself or others (e.g. incurable, recurrence preventable), *timeline* – refers to the perceived time frame of cancer growth, illness course, and recovery (e.g., acute, chronic, or cyclical) and *causes* – refers to the perceived cause of cancer (e.g. stress, unhealthy lifestyle, or family history), (Leventhal et al., 1992).

The constellation of these attributes will predict the perceived risk of cancer recurrence and inform the coping response chosen by the patient to manage emotional (emotion focused coping) and/or illness outcomes (problem-focused coping) (Hagger, Koch, Chatzisarantis, & Orbell, 2017). Higher perceived risk of cancer recurrence tends to elicit coping responses to manage emotional outcomes, such as FCR (Lee-Jones et al., 1997). In chronically ill patient samples, illness identity, consequences, and timeline are often predictive of emotion-focused coping, while perceived control over health and appraisal of coping are more related to problem-focused coping (Hagger et al., 2017; Richardson, Schüz, Sanderson, Scott, & Schüz, 2016). Health behaviours are generally conceptualized as problem-focused coping to manage illness outcomes (Hagger et al., 2017; Richardson et al., 2016), however they have been shown to help manage emotional outcomes such as depression and quality of life (Aguñaga et al., 2018). From a theoretical standpoint, their relationship with FCR remains unclear.

Conceptualizing Health Behaviours as a Coping

Based on the CSM, if health behaviours are a coping response to FCR, cancer survivors with greater perceived risk of cancer recurrence are expected to engage in more physical activity and fruit and vegetable intake. Subsequently, if survivors perceive greater self-efficacy to manage health, FCR severity should reduce. The few studies using the CSM framework to test the relationship between perceived risk of cancer recurrence, physical activity and fruit and vegetable intake, have yielded mixed results (Burris, Jacobsen, Loftus, & Andrykowski, 2012;

Costanzo, Lutgendorf, & Roeder, 2011; Green, Steinnagel, Morris, & Laakso, 2014; McGinty, Goldenberg, & Jacobsen, 2012; Mullens, McCaul, Erickson, & Sandgren, 2004). This may be attributed to inconsistencies in measurement of health behaviour constructs.

Illness representation and health behaviours. Studies measuring self-report changes in health behaviours have generally found that greater perceived risk of cancer recurrence (illness representation) is associated with increase in health behaviours (Burriss et al., 2012; Costanzo et al., 2011; Green et al., 2014; Mullens et al., 2004). However, it remains unclear which illness representation attributes best predict physical activity and healthy eating. One longitudinal study looking at 79 breast cancer survivors from 3 weeks to 3 months post-treatment found that survivors who perceived greater cancer consequences, attributed cause of cancer to poor diet or lack of exercise, and believed that health behaviours could help prevent cancer recurrence, reported significantly more physical activity and healthy dietary changes (Costanzo et al., 2011). In contrast, another cross-sectional study of 145 breast cancer survivors and 92 prostate cancer survivors, found that greater personal control and lower illness identity were associated with self-report increase in the same health behaviours (Green et al., 2014).

In other studies using standardized measures of physical activity and healthy diet, most illness representation attributes did not predict health behaviours (Burriss et al., 2012; Green et al., 2014; McGinty et al., 2012; Mullens et al., 2004). Belief that health behaviours can prevent cancer recurrence and contribute to overall health was the only predictor of adherence to physical activity and healthy diet in cancer survivors (Burriss et al., 2012; Mullens et al., 2004). Overall, current findings on the association between illness representation attributes and health behaviours are limited and contradictory. Moreover, the strength and direction of the relationships remains unclear. Further investigations are required to clarify which illness

representation attributes best predict health behaviours using standardized measures of physical activity and diet to obtain a more accurate representation of health behaviour practices.

Appraisal and FCR. As described previously, an important component of the CSM is the individual's appraisal of coping. One longitudinal study of 161 breast cancer survivors found that the interaction between higher perceived risk of cancer recurrence and negative appraisal of coping efficacy significantly predicted higher FCR severity. However, on its own, appraisal was not associated with FCR severity (McGinty et al., 2012). While the research on appraisal of coping is sparse, the perceived self-efficacy to manage health, a similar construct, is more frequently measured. A few studies found that perceived self-efficacy to complete physical activity and dietary recommendations, was associated with adherence to health behaviours (Burriss et al., 2012; Green et al., 2014; Mullens et al., 2004).

While the above-mentioned studies began the meticulous task of uncovering the relationship between FCR and health behaviours using the CSM, they are restricted to one or two disease sites, and confined to early survivorship (i.e. two years post active treatment, (Stanton, Rowland, & Ganz, 2015)). Further investigations are required to clarify the contradictory findings using a large sample of survivors with a range of cancer diagnoses. Moreover, accounting for FCR severity while examining the relationship between FCR and health behaviours within the model is imperative, given the emerging empirical evidence that cancer survivors can be classified in three FCR severity sub-groups: low, moderate and high, which have distinct survivorship profiles and patient characteristic (Séguin Leclair, Lebel & Westmaas, accepted 2019; Simard & Savard, 2009; Simonelli et al., 2017).

Study Objectives

Using the CSM's theoretical formulation of FCR, this cross-sectional study aimed to

explore the relationship between health behaviours (physical activity and fruit and vegetable intake) and FCR in a population-based sample of 10 cancer sites categorised by FCR severity groups (see figure 1). With the conceptualization that physical activity and fruit and vegetable as a coping response to FCR, the following relationship in the CSM were expected.

1) The authors hypothesized the following relationships between illness representation attributes and health behaviours (physical activity and fruit and vegetable intake): a- Illness identity & Consequences: cancer survivors who had a worse perception of their health and illness consequences were expected to report more health behaviours. b- Control over health: survivors who perceived more control over their health were expected to report more health behaviours. c- Timeline: survivors who viewed cancer as chronic were expected to report more health behaviours. 2) Health behaviours – appraisal: survivors who report more health behaviours were expected to positively appraise their self-efficacy to manage health. 3) Appraisal – FCR: survivors who positively appraise their self-efficacy to manage health were expected to have lower FCR severity. Overall, the hypothesized model was expected to show a good fit across FCR severity groups. The authors had no hypotheses concerning specific paths by FCR group, given that this is the first study to distinguish between FCR groups when testing the CSM. The authors hypothesised similar trends for both health behaviours; physical activity and fruit and vegetable intake (Burriss et al., 2012; Costanzo et al., 2011; Green et al., 2014; Mullens et al., 2004).

Method

Procedure

The current cross-sectional study is part of a larger longitudinal study examining FCR and health behaviours (Séguin Leclair et al., accepted 2019) using data from the American

Cancer Society's Study of Cancer Survivors-I (SCS-I), a national prospective longitudinal study of American cancer survivors with data collected in three waves beginning in 2000, T1, $M = 1.3$ years ($SD = 0.32$), T2, $M = 2.2$ years ($SD = 0.34$), and T3, $M = 8.8$ years ($SD = 0.63$) post cancer diagnosis. Analyses were conducted on third wave data as it was the only timepoint that CSM constructs were measured. Participant eligibility criteria were the following: diagnosed with one of the ten most highly incident cancers (prostate, breast, lung, colorectal, bladder, non-Hodgkin lymphoma (NHL), skin melanoma, kidney, ovarian, and uterine), over 18 years old at diagnosis, residing in one of the target states at the time of diagnosis, and diagnosed with a local, regional, or distant SEER Summary Stage cancer. Survivors were ineligible for the study if they were unable to complete the survey due to mental incompetence, unable to communicate in English or Spanish, or had terminal illness (Smith et al., 2007). The studies were approved by the Institutional Review Board of Emory University (Atlanta, GA), for each state, including the Connecticut Department of Public Health Human Investigation Committee, and the University of Ottawa Research and Ethics Board (Ottawa, Ontario). Additional details on recruitment and methodology are available elsewhere (Smith et al., 2007).

Measures

Socio-demographic and medical characteristics. The following socio-demographic and medical variables were examined and controlled for: age at diagnosis, sex, ethnicity, education, cancer site and cancer stage (Séguin Leclair et al., accepted 2019). Relationship status, family income and occupation were included for sample description purposes.

Measures of the Common-Sense Model Variables

Illness representation attributes.

Illness identity & consequences. Illness identity and consequences was measured using

the Medical Outcomes Study Short Form - Physical Health subscale (Ware, Kosinski, & Keller, 1996). Using a five-point Likert scale, respondents indicated their perception of physical functioning, impact of health on various roles, bodily pain and general health. This measure has good test-retest reliability after two weeks ($r = 0.86$) and construct validity ($r = 0.91$) with the original Medical Outcomes Study Form. Final scores ranging from 0-100 were obtained by computing items scores and comparing them to age-specific reference groups. Higher scores indicated a better perception of health and less illness consequences.

Control over health. To measure perceived control over health, eleven items from a measure of perceived barriers to health behaviours, were used to determine respondents' impression of their ability to control their health. Examples of items were "*Eating healthy foods will help me avoid getting cancer again*" and "*I am physically unable to exercise*". They were rated on five-point Likert scales ranging from strongly disagree to strongly agree. Total scores were computed, with higher scores indicating greater perceived barriers and therefore less control over health.

Timeline. Timeline refers to perceived chronicity of cancer recurrence and was assessed using the susceptibility subscale of the Revised Health Belief Model Scale (Champion, 1999). These three items used a five-point Likert scale ranging from *strongly agree* to *strongly disagree*; respondents indicated their perceived susceptibility of getting a cancer recurrence. It showed good internal consistency ($\alpha = 0.87$), good test-retest reliability after 6 weeks ($r = 0.62$), and good construct validity ($r = 0.87-0.91$) with original Susceptibility subscale of the Health Belief Model Scale (Champion, 1999). Total scores were computed, with higher scores indicating higher perceived chronicity of cancer.

Health Behaviours.

Physical activity. The Leisure-Time Exercise Questionnaire (LTEQ) was used in this study to assess physical activity. Respondents indicated the number of minutes they spent doing mild, moderate, and vigorous physical activity in a typical week (Godin & Shepard, 1985). The scale has shown good a test-retest reliability after two weeks ($r = 0.74$) and good convergent validity with maximum oxygen intake ($r = 0.83$) and values of body fat ($r = 0.85$) (Godin & Shepard, 1985). For the analysis, the total number of minutes spent doing moderate and vigorous physical activity weekly were computed (Kushi et al., 2012).

5-A-Day: Fruits and Vegetables. The 5-A-Day measure is a one item questionnaire developed by the ACS to measure adherence to the recommended five servings of fruits and vegetables a day (Smith et al., 2007). Respondents indicated in a typical week in the past month, how many days per week they consumed the daily 5 servings of fruits and vegetables.

Appraisal. To measure the appraised self-efficacy to manage health, the 8-item Perceived Health Competence Scale was used (Smith, Wallston, & Smith, 1995). This measure has shown good internal consistency ($\alpha = 0.82-0.90$) and construct validity in healthy and chronically ill samples (Smith et al., 1995). Higher total scores indicate a greater self-efficacy to manage health.

Fear of Cancer Recurrence. Fear of cancer recurrence was assessed using the severity subscale of the Fear of Cancer Recurrence Inventory (Simard & Savard, 2009). Comprised of 9 items, this subscale is considered the gold standard measure of FCR (Simard & Savard, 2009; Thewes et al., 2012). The subscale score which ranges from 0 to 32, has good internal consistency ($\alpha = 0.89$) and good test-retest reliability after one month ($r = 0.80$) (Simard & Savard, 2009). The initial cut-off score for clinical FCR was 13 (Simard & Savard, 2009) but additional studies have suggested cut-off scores of 16 and 22 (Fardell et al., 2018).

Data Analysis Strategy

Data were screened and cleaned using IBM SPSS 25. See Séguin Leclair et al., (accepted 2019) for detailed description of sample selection, descriptive analyses and group-based trajectory analyses used to establish the three FCR groups using longitudinal data: low FCR ($n = 786$, 33.6%), moderate FCR ($n = 1,357$, 58.1%) and high FCR ($n = 194$, 8.3%). Means, standard deviation, and bivariate correlations were computed for all model variables. Statistical assumptions for regression analysis were verified (Tabachnick & Fidell, 2012).

Path analysis was conducted to test the hypothesized model using IBM AMOS at a level of significance $p < 0.05$. Path coefficients were standardised to facilitate comparison and interpretation of data. Model fit was established using the following goodness-of-fit indices with corresponding criteria's, a small and non-significant chi-square likelihood ratio statistic (χ^2), comparative fit index (CFI) $\geq .95$, and root mean square error of approximation (RMSEA) $\leq .06$ (Hayduk, Cummings, Boadu, Pazderka-Robinson, & Boulianne, 2007). Using the modification indices proposed by AMOS, additional regression weights were sequentially added to the model until the goodness-of-fit indices reached previously mentioned criteria. Concurrently, theoretical meaning was considered before the addition of parameters in the model. Adequate sample size was reached for the total sample and FCR groups, since with 19 model parameters the minimum sample size required is $n = 190$, considering the suggested 10 participants/parameters (Kline, 2015). Given that variables met the normality assumed, the maximum likelihood estimation method was carried out.

Using the path analysis strategy described above, model optimization was accomplished in two steps to identify the model with the best fit for each of the three FCR groups. In the first step, the fit of the hypothesized model was assessed and improved using the total sample. The

improved model was then independently tested in the low, moderate, and high FCR groups to determine if the model was appropriate for each FCR severity groups. In the second step, the fit of the hypothesized model was once again tested, however this time the assessment and improvement of the model was done independently for the low, moderate and high FCR groups, which yielded three distinct models by FCR severity. As a final step, if the improved models in step 1 and step 2 differed within a FCR group, the goodness-of-fit indices were compared to select the model that best describes the data for that particular FCR group. In the case that the low, moderate or high FCR models were identical, pairwise comparison analyses with a corrected Bonferroni alpha at a level of significance of $\alpha = 0.01$; $Z \geq \pm 3.29$ were ran to formally compare model parameters between the identical models.

Results

Study sample

The 2,337 participants in this sample were mostly Caucasian (89.9%) women (60.4%) with college education or more (68%) and with a mean age of 56 at diagnosis. The most common cancer sites were breast (28.6%), prostate (21%), and colorectal (13.6%). See table 1 for all participants socio-demographic and medical characteristics.

Descriptive statistics and correlations for model variables

Table 2 in supplemental material, displays the means, standard deviations, and bivariate correlations for the 7 variables (illness identity & consequences, control over health, timeline, physical activity, fruit and vegetable intake, appraisal and FCR) in the hypothesized model by FCR groups.

Step 1: Model fit using the total sample

Using the total sample, the hypothesized model was tested and yielded poor goodness-of-

fit indices, $\chi^2 = 1718.72$, $p < 0.001$; CFI = 0.49; RMSEA = 0.29 (see figure 2a). By adding four additional paths as suggested by the modification indices, the model fit improved with a $\chi^2 = 38.12$, $p < 0.001$; CFI = 0.99; RMSEA = 0.05 (see figure 2b). The chi-square likelihood ratio statistic remained significant, but the model was deemed acceptable given large sample size. When testing the improved model in each FCR severity group, it showed a good fit for the low FCR group $\chi^2 = 15.21$, $p = 0.01$; CFI = 0.99; RMSEA = 0.05, moderate FCR group $\chi^2 = 22.37$, $p < 0.001$; CFI = 0.99; RMSEA = 0.05 and high FCR group $\chi^2 = 8.26$, $p = 0.14$; CFI = 0.99; RMSEA = 0.06.

Step 2: Model fit using the low, moderate, and high FCR groups

Similar to the total sample, the hypothesized model showed a poor fit for the low FCR group $\chi^2 = 457.62$, $p < 0.001$; CFI = 0.5; RMSEA = 0.25, moderate FCR group $\chi^2 = 903.41$, $p < 0.001$; CFI = 0.47; RMSEA = 0.27 and high FCR group $\chi^2 = 123.59$, $p < 0.001$; CFI = 0.53; RMSEA = 0.26. Models were then independently improved using the suggested modification indices. The low and moderate FCR groups yielded the same model as previously identified using the total sample (see figure 3a-b). Meanwhile, the high FCR group yielded a different model with improved goodness-of-fit indices, $\chi^2 = 6.02$, $p = 0.3$; CFI = 1.0; RMSEA = 0.03 (see figure 3c). Four paths were added to the hypothesized model for the high FCR group with one path that was distinct from the low and moderate FCR models. Given that the final low and moderate FCR models were identical, pairwise comparisons were conducted to formally assess model parameter differences. Results showed that the timeline-FCR severity path was the only significantly different model parameter, $z = 4.28$. See figure 3 displaying the standardized coefficients and corresponding significance for paths in the three final models by FCR group.

Final low and moderate FCR models

Illness representation and health behaviours. In the low and moderate FCR groups, survivors who had a better perception of cancer and its consequences reported significantly more physical activity. However, perception of cancer and its consequences was unrelated to fruit and vegetable intake. Similarly, perceived chronicity of cancer was unrelated to fruit and vegetable intake. In the moderate FCR group, survivors who viewed cancer as chronic reported less physical activity. In comparison, no such relationship was found in the low FCR group. In both FCR groups, survivors who perceived more control over their health reported more physical activity and fruit and vegetable intake.

Health behaviours and appraisal. Cancer survivors who engaged in more physical activity and fruit and vegetable intake positively appraised their self-efficacy to manage health.

Appraisal and FCR. In the low FCR group, survivors who positively appraised their self-efficacy to manage health had lower FCR severity, however this relationship was weak (standardized $\beta = -0.066$, $p = 0.04$). Moreover, this relationship was non-existent in the moderate FCR group.

Additional paths. In the low and moderate FCR models, the same four additional paths were added to improve model fit. The first path revealed that survivors who view cancer as chronic experienced higher FCR severity. The second, third, and fourth path involved components of the perceived risk of cancer recurrence and appraisal. Survivors who had a worse perception of cancer and its consequences, perceived less control over their health, and viewed cancer as chronic negatively appraised their self-efficacy to manage health.

Final high FCR model

Illness representation and health behaviours. In high FCR group, similarly to the low

and moderate FCR groups, survivors who had a better perception of cancer and its consequences reported significantly more physical activity. Moreover, perception of cancer and its consequences was unrelated to fruit and vegetable intake. Similarly, perceived chronicity of cancer was unrelated to fruit and vegetable intake. In the high FCR group, survivors who viewed cancer as chronic reported more physical activity, which was opposite to survivors in the moderate FCR group, who reported less physical activity. Moreover, no such relationship was found in the low FCR group. Similarly, to the low and moderate FCR groups, survivors in the high FCR group who perceived more control over their health reported more physical activity and fruit and vegetable intake.

Health behaviours and appraisal. In the high FCR group, the amount of physical activity and fruit and vegetable intake reported by survivors was unrelated to the self-efficacy to manage health. Interestingly, this relationship was significant in the low and moderate FCR groups; survivors who engaged in more health behaviours in these groups reported greater self-efficacy to manage health.

Appraisal and FCR. Cancer survivors who reported a greater self-efficacy to manage health had lower FCR severity. In comparison, the same relationship was weakly significant in the low FCR group and non-existent in the moderate FCR group.

Additional paths. Four additional paths were added to the high FCR model to improve model fit. The first three paths were identical to the paths added in the low and moderate FCR groups. The first path revealed that survivors who view cancer as chronic experienced higher FCR severity and the second and third paths, showed that survivors who had a worse perception of cancer and its consequences and perceived less control over their health reported lower self-efficacy to manage health. Unique to the high FCR group, the fourth path revealed that survivors

who perceived less control over their health also reported less FCR severity.

Discussion

The goal of this study was to explore the relationship between health behaviours (physical activity and fruit and vegetable intake) and FCR in a population-based sample of mixed cancer survivors categorised by FCR severity groups using the CSM's theoretical formulation of FCR. The hypothesized model initially yielded poor fit indices but with the addition of four regression paths the final low, moderate, and high FCR models showed a good fit. Interestingly, the final low and moderate FCR models were the same while the high FCR model differed by one regression path. These findings contribute to empirical evidence that there may be subtle differences between FCR sub-groups, which should be accounted for when conducting research on FCR (Séguin Leclair et al., accepted 2019; Simonelli et al., 2017).

Health Behaviours and FCR

Contrary to the overarching hypothesis, engaging in health behaviours did not influence FCR in most of the participants in the present study. Only in the low FCR group was a weak relationship found. In this sub-group, cancer survivors reporting more health behaviours had a greater self-efficacy to manage health, which in turn predicted lower FCR severity. Nonetheless, the CSM mapped on well to the data, revealing other important relationships predicting health behaviours in cancer survivors.

Illness representation predicting health behaviours

As hypothesized, across FCR groups, survivors who perceived more control over their health reported more physical activity and fruit and vegetable intake. These results are congruent with the body of CSM literature, where perceived control is an important indicator of health behaviours in chronically ill samples (Hagger et al., 2017; Richardson et al., 2016). Although

past studies suggest that health behaviours behave similarly in the CSM (Burriss et al., 2012; Costanzo et al., 2011; Green et al., 2014; Mullens et al., 2004), in this sample, physical activity and fruit and vegetable intake yielded distinct relationships with other illness representation attributes. Given that health behaviours are conceptualized as coping responses to illness representation, this could be explained by the perceived usefulness of physical activity in managing cancer risk in comparison to healthy diet. Interestingly, a recent qualitative study found that some cancer survivors do not engage in health behaviours because they do not accept the link between health behaviours and cancer (Corbett et al., 2018). Meanwhile, other survivors accept this link but report barriers to engage in a healthy lifestyle (Corbett et al., 2018). Future research should examine cancer survivor's beliefs regarding the usefulness of physical activity compared to fruit and vegetable intake to reduce risk of cancer recurrence.

Contrary to the hypothesis, cancer survivors who had a better perception of cancer and its consequences reported more physical activity, across FCR groups. This suggests a favorable view of health is predictive of physical activity. A similar pattern was found in the moderate FCR group, where cancer survivors, who viewed cancer as chronic, reported less physical activity. Meanwhile, the survivors in the high FCR group reported more health behaviours if they viewed cancer as chronic. This suggests that reasons for engaging in physical activity may be nuanced by FCR severity, and that the theoretical assumption, whereby a greater perceived risk of cancer recurrence mobilizes engagement in health behaviours, may only apply to a subset of cancer survivors (Demark-Wahnefried et al., 2005; Lee-Jones et al., 1997). Moreover, these findings suggest the constellation of illness attributes predicting coping responses may be more complex than previously anticipated, which could explain the mixed findings from previous CSM research in cancer survivors (Burriss et al., 2012; Costanzo et al., 2011; Green et al., 2014;

McGinty et al., 2012; Mullens et al., 2004).

Health behaviours as a coping response

Although health behaviours were mostly unrelated to FCR in this sample of cancer survivors, their relationship with other CSM components confirms their conceptualization as problem-focused coping behaviours used to manage illness outcomes. As previously mentioned, coping behaviours can be classified in two categories: emotion-focused and problem-focused, used to manage emotional and illness outcomes, respectively (Hagger et al., 2017; Richardson et al., 2016). While emotion-focused coping tends to be associated with illness identity, consequences, and timeline, problem-focused coping is strongly related to perceived control and appraisal (Hagger et al., 2017; Richardson et al., 2016), which is what was found in the present study.

Low and moderate FCR groups. In the low and moderate FCR groups, health behaviours were strongly related to control over health and self-efficacy to manage health, which suggests that survivors engaged in these behaviours to manage illness outcomes. Congruently, in past studies, perceived self-efficacy to engage in physical activity and healthy diet was a better predictor of adherence to health behaviours than the perceived risk of cancer recurrence. (Burriss et al., 2012; Green et al., 2014; McGinty et al., 2012; Mullens et al., 2004).

High FCR group. Meanwhile, in the high FCR group, appraisal was unrelated to health behaviours, but associated to FCR. This suggests that for cancer survivors reporting high FCR, their self-efficacy to manage health is a better predictor of FCR than engaging in physical activity and fruit and vegetable intake. Past CSM studies in cancer survivors found a similar relationship, where self-report changes or intent to engage in health behaviours was associated to perceived risk of cancer recurrence while engagement in health behaviours was unrelated (Burriss

et al., 2012; Costanzo et al., 2011; Green et al., 2014; Mullens et al., 2004). Moreover, as seen in Séguin Leclair et al., accepted 2019, cancer survivors in the high FCR group engaged in less health behaviours than other survivors. Therefore, in the high FCR group, health behaviours do not appear to be an adaptive coping response to manage FCR.

Predictor of FCR outcomes

Although the relationship between health behaviours and FCR was weaker than anticipated, additional paths in all three models revealed other factors predicting FCR severity. Across FCR groups, timeline was the greatest predictor of FCR, congruent with previous studies (Moon, Moss-Morris, Hunter, & Hughes, 2017; Phillips et al., 2013). No additional factors predicted FCR in the low and moderate FCR groups. In the high FCR group, survivors who had a worse perception of cancer and its consequences and perceived less control over their health reported lower self-efficacy to manage health, which in turn predicted higher FCR. Furthermore, in the same group, an unexpected path emerged where survivors who perceived less control over their health reported less FCR. This relationship can be interpreted in two ways; perceiving more control over health predicts more FCR, or perceiving less control over health predicts less FCR. Both interpretations are probable and could be highlighting maladaptive patterns (i.e., excessive copers and avoiders) commonly seen in highly distressed cancer survivors (Thewes, Lebel, Seguin Leclair, & Butow, 2015).

Clinical Implications

Managing FCR. While health behaviours did not influence FCR in most participants, this study found preliminary evidence that engaging in physical activity or consuming fruits and vegetables could be beneficial to manage FCR in survivors with low FCR. As suggested in stepped care models, these patients could benefit from educational programs on health

behaviours to help manage FCR (Stanton, 2012). The remainder of the CSM showed a good fit across participants, further supporting for the use of the CSM in current FCR conceptualizations (Fardell et al., 2016; Lebel et al., 2014; Simonelli et al., 2017) and interventions (Butow et al., 2017; Lebel et al., 2014; Maheu et al., 2016). Timeline stood out as the strongest predictor of FCR in the model across FCR groups, hence interventions targeting the perceived chronicity of cancer recurrence may help cancer patients manage their FCR. The distinction between the low/moderate and high FCR models supports the postulate that interventions should be tailored by FCR severity given the different needs of cancer survivors (Ratcliff, Naik, Martin, & Moye, 2017). However, all current FCR interventions only target patients with high FCR severity (Butow et al., 2017; Lebel et al., 2014).

In the high FCR group, self-efficacy to manage health was strongly associated with FCR. Therefore, improving cancer survivors' self-efficacy to manage health could be an important FCR intervention target. As previously suggested, cancer survivors' perceived control over their health could be predicting two distinct responses to FCR: excessive coping or avoiding (Thewes et al., 2015). In this case, health care providers could tailor their approach when communicating health behaviour recommendations to better suit survivors' coping style.

Health Behaviour Interventions. The disparities between physical activity and fruit and vegetable intake in this sample suggest that cancer survivors have distinct beliefs concerning the usefulness of health behaviours to reduce risk of cancer recurrence. In addition, perceived control over health was the greatest predictor of engagement in these health behaviours across FCR groups. Hence, cancer survivors could benefit from a two-fold intervention: first, targeting beliefs concerning the usefulness of health behaviours to manage cancer risk, and second, increasing perceived control over health (Corbett et al., 2018).

Interventions targeting health behaviours could be tailored by FCR severity. As positive appraisal of self-efficacy to manage health predicted more health behaviours only in cancer survivors with low to moderate FCR, targeting this factor in survivors with low to moderate FCR may be beneficial, but likely unsuccessful for survivors with high FCR. As suggested in previous studies, survivors with high FCR are primarily focused on emotion-coping given higher distress levels and preoccupation, impacting their ability to adhere to healthy lifestyles (Mutsaers et al., 2016). Hence, for these cancer survivors, managing FCR first might be required prior to any successful health behaviour interventions.

Study limitations

This study was limited by its cross-sectional design, capturing FCR and health behaviours later in the cancer survivorship trajectory. While FCR was found to be stable in this group (Séguin Leclair et al., accepted 2019), factors in the CSM model have been shown to fluctuate in time (Leventhal, Phillips, & Burns, 2016). Therefore, using a static measurement protocol might not be representative of cancer survivors' responses across survivorship. Future studies should monitor health behaviours and CSM factors periodically throughout the survivorship trajectory (Leventhal et al., 2016). This study used self-report questionnaires, therefore data is susceptible to the respondents' ability to recall and social desirability. While the questionnaires used to assess illness representation components in this study were adequate measures of the constructs, the Revised Illness Perceptions Questionnaire was not used in this study (Moss-Morris et al., 2002). Given that this measure is commonly used in other CSM studies, this limits generalizability across studies. Moreover, the perceived cause of cancer recurrence, another component of illness representation in the CSM model, was not included in the original survey questionnaire. As previous studies have consistently shown, causal attribution

of cancer to poor diet or lack of exercise predicts adherence to health behaviours (Burriss et al., 2012; Costanzo et al., 2011; Mullens et al., 2004); the absence of this measure might limit the understanding of factors predicting health behaviours. Health behaviour practices prior to cancer diagnosis were not measured in this study, nor were motivations for engaging in health behaviours. Therefore possible explanations for the relationship between factors have been extrapolated from the empirical data and informed by theoretical formulation, however these inferences need to be confirmed in future studies. Further investigations are required to explore cancer survivors' motivations to engage in specific health behaviours based on FCR severity.

Conclusion. Overall, the CSM showed a good fit. While identical models were yielded for the low and moderate FCR groups, the high FCR group was slightly different. This study found that engaging in physical activity or consuming fruits and vegetables did not influence FCR in most cancer survivors, except for those reporting low FCR. However, other elements of the CSM predicted FCR. Health behaviours are likely problem-focused responses to manage illness outcomes in cancer survivors. Further investigations are required to assess cancer survivors' perceived usefulness of physical activity and fruit and vegetable intake to manage the risk of cancer recurrence, taking into consideration FCR severity.

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Study 2: Tables and Figures

Table 1
Participant Characteristics, N = 2, 337

Variable	<i>M</i>	<i>SD</i>
Age at diagnosis (years)	56.22	11.19
Time since diagnosis (years)	8.8	0.63
	<i>n</i>	<i>%</i>
Sex		
Male	936	39.6
Female	1411	60.4
Ethnicity		
Caucasian	2100	89.9
African American	116	5
Hispanic	66	2.8
Other	45	1.9
Not indicated/missing	10	0.4
Education		
Highschool or less	727	31.1
College or more	1588	68
Not indicated/missing	22	0.9
Cancer Type		
Breast	668	28.6
Prostate	490	21
Colorectal	317	13.6
Uterine	152	6.5
NHL	152	6.5
Melanoma	139	5.9
Kidney	127	5.4
Lung	103	4.4
Ovarian	100	4.3
Bladder	89	3.8
Cancer Stage		
Stage 0 – 1	1649	70.6
Stage 2- 3	688	29.4
Civil Status		
Married/Cohabiting	1813	77.6
Divorced/Separated	226	9.7
Widowed	145	6.2
Single	145	6.2
Not indicated/missing	8	0.3
Household Income		
0-9,999	57	2.4
10,000-19,999	144	6.2
20,000-39,999	456	19.5
40,000-74,999	749	32
75,000 or more	641	27.4
Not indicated/missing	290	12.4
Occupation		
Employed full-time	1127	48.2
Employed part-time	196	8.4
Retired	577	24.7
Homemaker	148	6.3
Leave or Unemployed due to illness	119	5.1
Unemployed	73	3.1
Student	9	0.4
Not indicated/missing	88	3.8

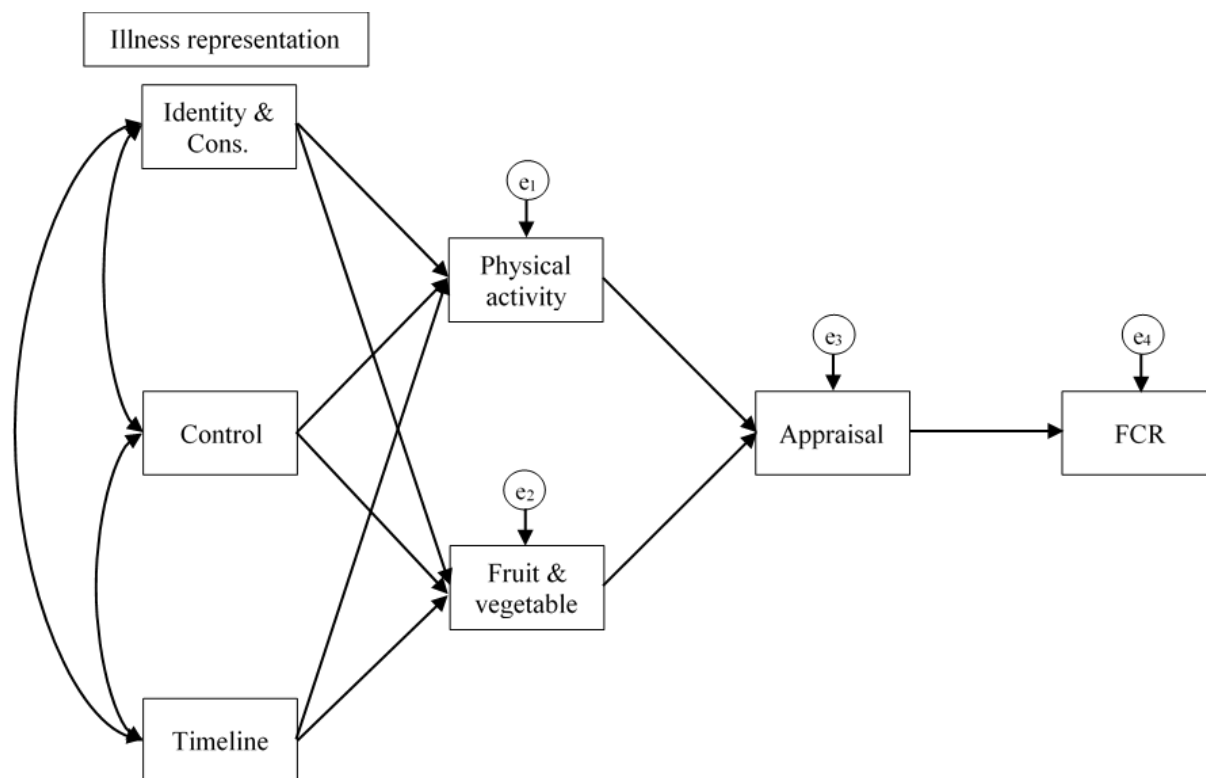


Figure 1. Part of the Theoretical FCR formulation based on the Common-Sense Model (Lee-Jones et al., 1997)

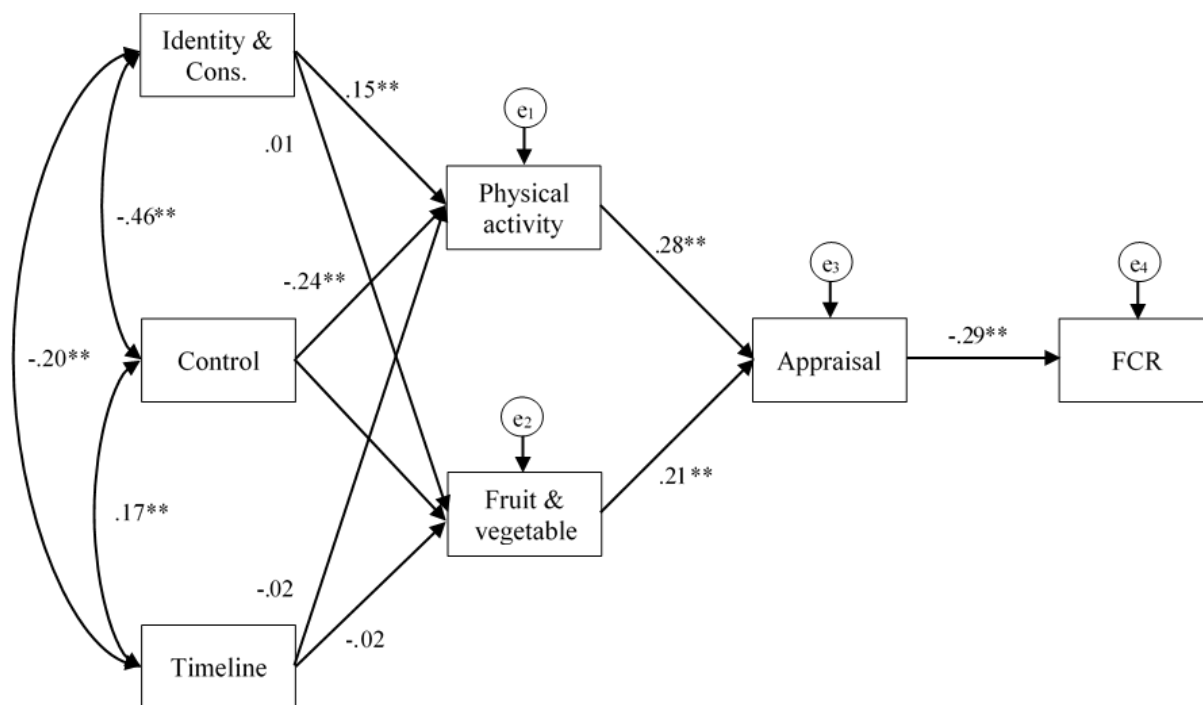


Figure 2a. Hypothesized model path analysis diagram with standardized coefficients for the total sample, ** $p < .01$

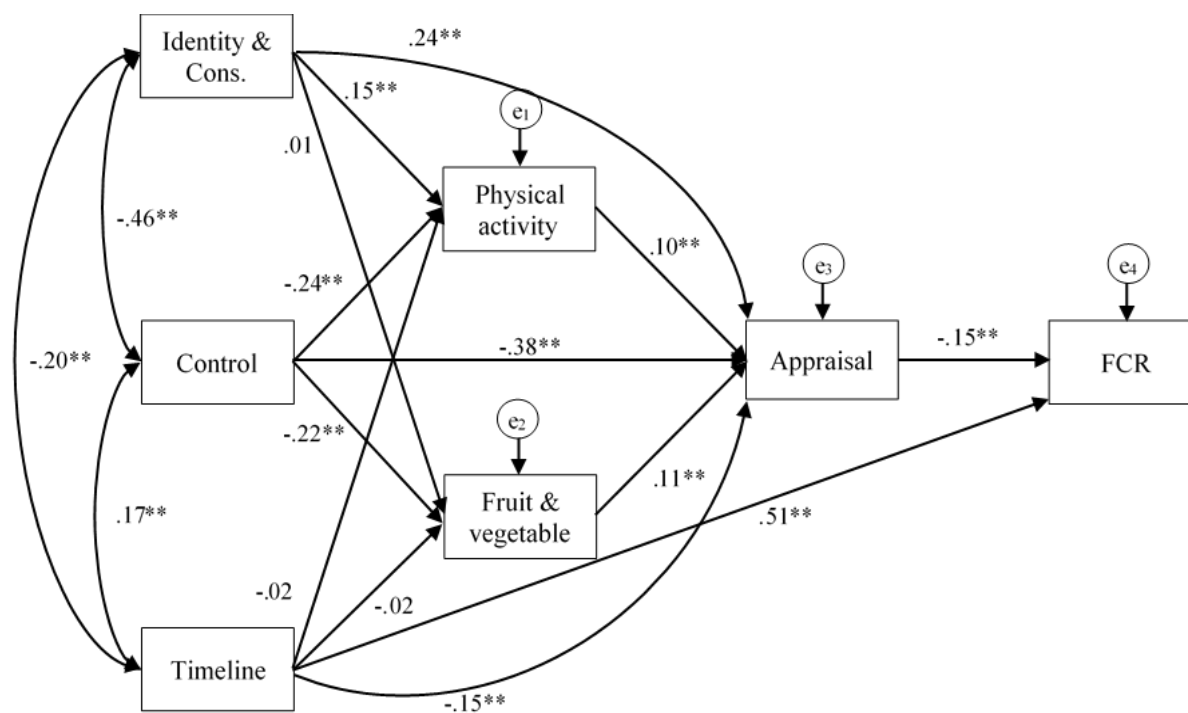


Figure 2b. Final model path analysis diagram with standardized coefficients for the total sample, ** $p < .01$

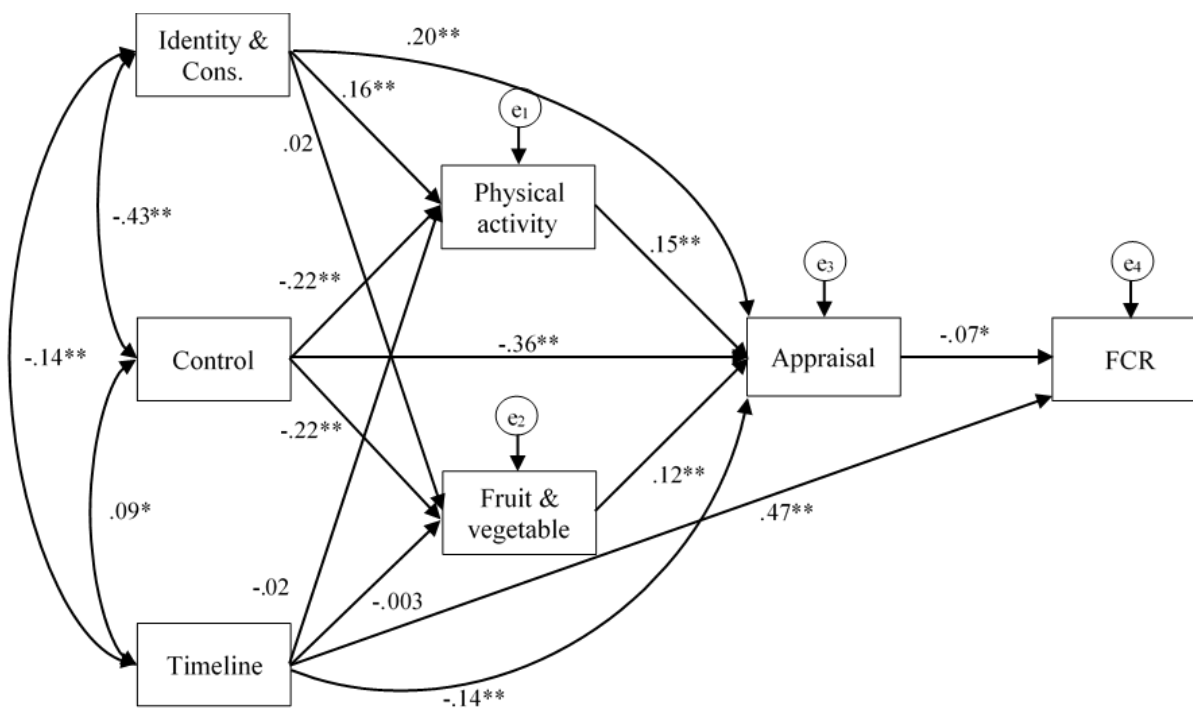


Figure 3a. Final model path analysis diagram with standardized coefficients for the low FCR group, ** $p < .01$, * $p = .04$

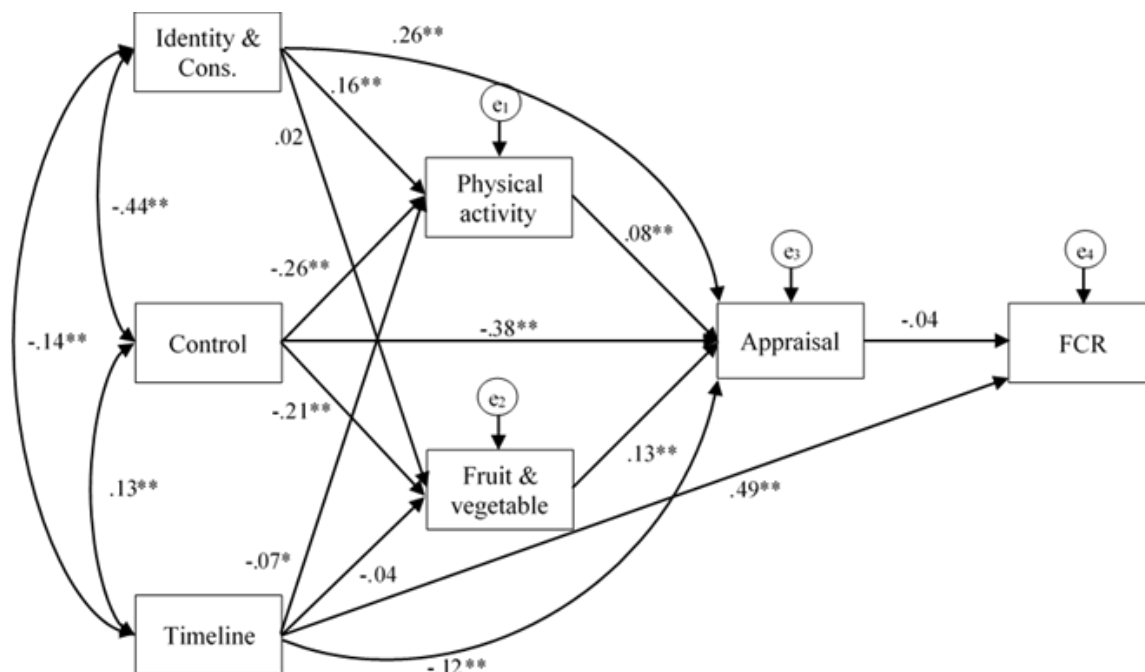


Figure 3b. Final model path analysis diagram with standardized coefficients for the moderate FCR group, ** $p < .01$

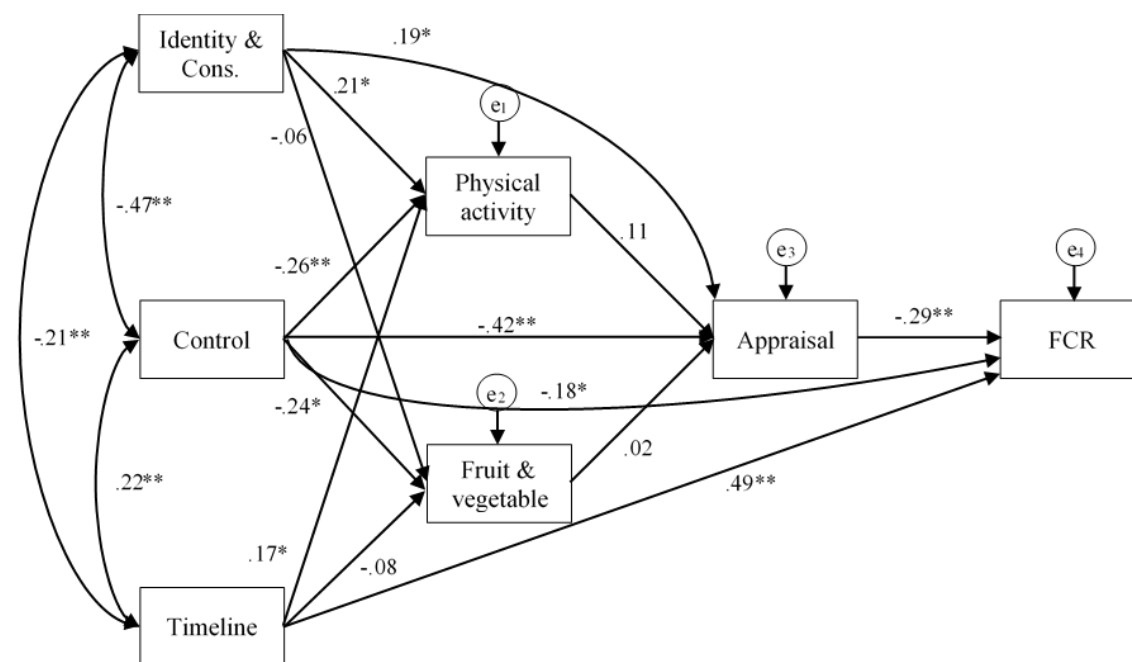


Figure 3c. Final model path analysis diagram with standardized coefficients for the high FCR group, ** $p < .01$

Supplemental Material

Table 2
Correlations among variables in the model by FCR group

Low FCR group, <i>n</i> = 786									
Variable	<i>M</i>	<i>SD</i>	1	2	3	4	5	6	7
1. Illness identity & Cons.	50.79	9.78	-						
2. Control	12.62	4.12	-.43**	-					
3. Timeline	7.35	2.65	-.14**	.09*	-				
4. Physical activity	101.44	161.09	.26**	-.29**	-.06	-			
5. Fruit and vegetable	3.43	2.2	.12**	-.23**	-.03	.17**	-		
6. Appraisal	3.74	0.58	.43**	-.53**	-.22**	.34**	.26**	-	
7. FCR	6.65	4.75	-.13**	.04	.48**	-.07	-.05	-.17**	-
Moderate FCR group, <i>n</i> = 1357									
Variable	<i>M</i>	<i>SD</i>	1	2	3	4	5	6	7
1. Illness identity & Cons.	47.97	10.91	-						
2. Control	13.72	4.48	-.44**	-					
3. Timeline	8.52	2.51	-.14**	.13**	-				
4. Physical activity	98.96	148.47	.27**	-.33**	-.12**	-			
5. Fruit and vegetable	3.32	2.13	.12**	-.22**	-.07*	.16**	-		
6. Appraisal	3.54	0.61	.48**	-.56**	-.22**	.31**	.26**	-	
7. FCR	12.76	6.14	-.15**	.071**	.5**	-.1**	-.014	-.15**	-
High FCR group, <i>n</i> = 194									
Variable	<i>M</i>	<i>SD</i>	1	2	3	4	5	6	7
1. Illness identity & Cons.	42.51	13.97	-						
2. Control	15.96	4.85	-.47**	-					
3. Timeline	10.19	2.51	-.21**	.22**	-				
4. Physical activity	72.44	125.97	.29**	-.32**	.07	-			
5. Fruit and vegetable	2.78	2.21	.04	-.2**	.04	.11	-		
6. Appraisal	3.08	0.68	.42**	-.55**	-.23**	.3**	.12	-	
7. FCR	21.18	6.90	-.12	.08	.51**	.04	.08	-.30**	-

Note. Cons., consequences, FCR, fear of cancer recurrence * $p < .05$, ** $p < .01$

General Discussion

Rational and Overview of Thesis Studies

This thesis reports on two studies that examined the relationship between FCR and health behaviours in a population-based sample of mixed cancer survivors categorised by FCR severity. Recognized as one of the most common concerns in cancer survivors (Simard et al., 2013), FCR manifests itself on a spectrum from normative worries to clinical levels with higher FCR predicting poor psychosocial outcomes and impaired functioning (Mutsaers et al., 2016). Classifying cancer survivors into FCR severity groups is an important first step to accurately screen for survivors at risk of poor psychological outcomes. Past studies have classified survivors in three sub-groups: low, moderate, and high FCR severity. There is preliminary evidence that cancer survivors in these sub-groups have distinct characteristics and follow distinct patterns of FCR changes over time (Melchior et al., 2013; Savard & Ivers, 2013). However, the prevalence of survivors in each sub-group remains unclear and few studies were longitudinal, therefore additional analyses were needed to examine FCR trajectories from early to long-term survivorship, across cancer sites.

Cancer is often conceptualized as a "teachable moment" motivating cancer survivors to engage in a healthy lifestyle. There is growing empirical evidence that a healthy lifestyle can help prevent cancer recurrence and maintain overall health in cancer survivors (Davies, Batehup, & Thomas, 2011; Pekmezi & Demark-Wahnefried, 2011). However, the majority of cancer survivors do not adhere to recommended American Cancer Society (ACS) guidelines (Kushi et al., 2012) of at least 150 minutes of moderate physical activity, or 75 minutes of vigorous physical activity weekly, and the intake of at least five portions (5-a-day) of fruits and vegetables each day (Blanchard, Courneya, & Stein, 2008; Bluethmann et al., 2015; Brunet, Amireault,

Chaiton, & Sabiston, 2014; Hawkins et al., 2017; LeMasters, Madhavan, Sambamoorthi, & Kurian, 2014). While several studies have assessed the prevalence of health behaviours cross-sectionally, only a few studies have looked at changes in physical activity and fruit and vegetable intake over time (Brunet, Amireault, Chaiton, & Sabiston, 2014; Costanzo, Lutgendorf, & Roeder, 2011; Williams, Steptoe, & Wardle, 2013). Early findings suggest that physical activity and fruit and vegetable intake remains stable over time (Brunet et al., 2014; Costanzo et al., 2011; Williams et al., 2013), and that cancer survivors follow distinct physical activity trajectories over time (Brunet et al., 2014). Further investigations were required to examine health behaviour practices in cancer survivors from early to long-term survivorship.

Theoretically, FCR is conceptualized has a motivating factor, enticing cancer survivors to engage in health behaviours (Demark-Wahnefried, Aziz, Rowland, & Pinto, 2005; Lee-Jones, Humphris, Dixon, & Bebbington Hatcher, 1997). Thus far, the few studies looking at the association between FCR and physical activity/dietary changes in cancer survivors report conflicting results (Fisher, Beeken, Heinrich, Williams, & Wardle, 2016). Therefore, study 1 aimed to examine the association between FCR and health behaviours across the survivorship trajectory.

The Leventhal Common-Sense Model (CSM) is the most comprehensive and evidenced-based theoretical approach applied to FCR (Fardell et al., 2016) and it is frequently used to predict health behaviours in chronically ill patients (Leventhal, Diefenbach, & Leventhal, 1992). In study 2, the CSM theoretical framework was used to further examine the relationship between FCR and health behaviours (physical activity and fruit and vegetable intake). While there was preliminary evidence that components of the CSM can be applied to the relationship between FCR and health behaviours, conflicting findings also emerged. The aim of study 2 was to clarify

these findings using a large sample of cancer survivors with mixed cancer sites in long-term survivorship. The CSM was tested on three distinct FCR severity groups: low, moderate and high, to adequately capture the full range of FCR manifestation in cancer survivors.

This general discussion will provide an overview of the study findings, integrate these findings to the existing literature including relevant theoretical models, and present the studies' limitations, clinical implications, and future research directions.

Study 1: Review of Objectives and Hypotheses. To review, the purpose of the first study was to clarify the relationship between FCR and health behaviours (physical activity and fruit and vegetable intake) from early to long-term survivorship. The first objective was to identify distinct longitudinal FCR trajectories, by clustering cancer survivors following a similar FCR progression. FCR severity and patient characteristics associated with each trajectory group were then formally compared. The authors hypothesised that three distinct FCR trajectories: low, moderate, and high FCR would be identified. FCR was hypothesised to significantly decrease over time across all three trajectories but the higher FCR group was expected to show a greater reduction in FCR than the other groups. Patients with the following characteristics: younger age, female, Hispanic ethnicity, and high school education or less were expected to be more prevalent in the high FCR group. Given the weak evidence, no hypotheses were noted regarding cancer stage or cancer site between trajectory groups.

The second objective was to explore the physical activity and fruit and vegetable intake reported by cancer survivors, first by comparing these behaviours between trajectory groups and over time, and second by establishing the rate of adherence to recommended health behaviours and comparing them by trajectory group. The high FCR group was expected to report more physical activity and fruit and vegetable intake than the moderate and low FCR groups.

Moreover, as FCR decreases over time physical activity and fruit and vegetable intake was expected to also decrease across time in all three trajectory groups.

Study 1: Main Findings. The first study found three FCR trajectories from early to long-term survivorship clustering cancer survivors by FCR severity: low (33.6%), moderate (58.1%), and high (8.3%). FCR significantly decreased over time and remained distinct for each trajectory group. Patient characteristics prevalent in the high FCR group were being female, of younger age, Hispanic ethnicity, having more advanced cancer stage (II-III) and Non-Hodgkin lymphoma. Across FCR groups, only a minority of survivors adhered to the recommended physical activity and fruit and vegetable intake. A modest relationship between FCR severity and both health behaviours was found, where survivors in the high FCR group reported significantly fewer of these health behaviours than survivors in the low and moderate FCR groups, albeit with a small effect size.

Study 2: Review of Objectives and Hypotheses. Using the CSM's theoretical formulation of FCR, the study 2 aimed to explore the relationship between health behaviours (physical activity and fruit and vegetable intake) and FCR in a population-based sample of 10 cancer sites categorised by FCR severity groups. With the conceptualization that physical activity and fruit and vegetable as a coping response to FCR, the following relationship in the CSM were expected.

1) The authors hypothesized the following relationships between illness representation attributes and health behaviours (physical activity and fruit and vegetable intake): a- Illness identity & Consequences: cancer survivors who had a worse perception of their health and illness consequences were expected to report more health behaviours. b- Control over health: survivors who perceived more control over their health were expected to report more health behaviours. c-

Timeline: survivors who viewed cancer as chronic were expected to report more health behaviours. 2) Health behaviours – appraisal: survivors who report more health behaviours were expected to positively appraise their self-efficacy to manage health. 3) Appraisal – FCR: survivors who positively appraise their self-efficacy to manage health were expected to have lower FCR severity. Overall, the hypothesized model was expected to show a good fit across FCR severity groups. The authors had no hypotheses concerning specific paths by FCR group, given that this is the first study to distinguish between FCR groups when testing the CSM. The authors hypothesised similar trends for both health behaviours; physical activity and fruit and vegetable intake (Burriss et al., 2012; Costanzo et al., 2011; Green et al., 2014; Mullens et al., 2004).

Study 2: Main Findings. The second study found that engaging in physical activity and fruit and vegetable intake did not influence FCR in most participants. Yet, in the low FCR group, cancer survivors reporting more health behaviours had a better self-efficacy to manage health, which in turn predicted lower FCR severity. With the addition of four paths, the remainder of the CSM showed a good fit in the low, moderate and high FCR. The low and moderate FCR models were the same but the high FCR group was different.

In the low and moderate FCR groups, health behaviours were related to control over health and self-efficacy to manage health which suggested that cancer survivors use health behaviours to manage illness outcomes. For cancer survivors in the high FCR group, results indicated that self-efficacy to manage health is a better predictor of FCR than engaging in physical activity and fruit and vegetable intake. Across FCR groups, timeline was the greatest predictor of FCR. No additional factors predicted FCR in the low and moderate FCR groups. However, among those in the high FCR group, survivors who had a worse perception of cancer

and its consequences and perceived less control over their health reported lower self-efficacy to manage health, which in turn predicted higher FCR. In addition, survivors with high FCR who perceived less control over their health reported less FCR, which can be interpreted in two ways; perceiving more control over health predicts more FCR or perceiving less control over health predicts less FCR.

Reflection on Thesis Objectives

Overall, this thesis had three main objectives: 1) to establish the presence of subgroups related to FCR severity (i.e., low, medium, high); 2) to examine the relationship between FCR and health behaviours over time; and 3) to further examine the relationship between FCR and health behaviours cross-sectionally using the CSM. Given the mixed empirical findings between FCR and health behaviours, thesis hypotheses were extrapolated from theoretical frameworks, including the “teachable moment” theory and Leventhal’s theoretical formulation of FCR. Hence, the underlying thesis assumption was that higher FCR severity would be associated with greater physical activity and fruit and vegetable intake. Therefore, in study 1, we were expecting to find distinct levels of physical activity and fruit and vegetable intake by FCR severity group. Then in study 2, we wanted to expand these findings by examining the factors that predict the relationship using the CSM framework, which is the most sophisticated model applied to FCR and health behaviours.

Contrary to our hypothesis, in study 1 weak evidence supporting the relationship between FCR and health behaviours was found, and high FCR predicted fewer health behaviours. Therefore, the original justification for study 2 was no longer applicable. This led us to re-examine the purpose of study 2. In the process, we considered different ways to further explore the data. Given that the CSM is the best theoretical framework to examine health behaviours in

chronically ill patients, and has been empirically validated in cancer survivors, we opted to continue using this model to examine FCR and health behaviours in the thesis sample.

Integration of Findings with Existing Literature

Conjointly, the two studies suggest that cancer survivors can be categorized in three FCR severity sub-groups, and that these groups can be distinguished by individual characteristics and distinct patterns of interaction between variables pertinent to cancer survivorship. Although adherence to physical activity and fruit and vegetable intake was low over time and across FCR severity groups, the high FCR group reported significantly fewer of these health behaviours compared to the other groups. Moreover, it was only in the low FCR group that the practice of health behaviours indirectly predicted less FCR, through self-efficacy to manage health. In addition, the relationships in the CSM theoretical formulation of FCR suggest that cancer survivors in the low and moderate FCR groups engage in health behaviours to manage illness outcomes, and the high FCR group survivors' self-efficacy to manage health was deemed more relevant than the practice of health behaviours as the latter significantly predicted FCR severity. Hence, considering sub-groups has proven beneficial to uncover distinct manifestations of FCR.

FCR severity

These results support the categorization of cancer survivors in FCR severity groups given distinct patient characteristics and patterns of interaction in the CSM. Using a statistical method to cluster groups based on FCR severity over time was a novel approach of categorizing cancer survivors. Currently, identifying survivors with clinically significant FCR is a priority in FCR research (Sharpe, Thewes, & Butow, 2017). Thus far, the field has mostly relied on measurement cut-offs to identify survivors with high or "clinical FCR", but the features that differentiate high FCR levels from low to moderate levels are not yet clear (Mutsaers et al., 2016). Therefore, these

findings need to be carefully interpreted as FCR severity groups may not coincide with clinical FCR.

Physical Activity and Fruit and Vegetable Intake

As physical activity and fruit and vegetable intake yielded distinct relationships with other variables in the CSM, the thesis findings suggest that motivational factors might differ by health behaviour. Given that health behaviours are conceptualized as coping responses to illness representation, this could be explained by the perceived usefulness of physical activity in managing cancer risk in comparison to healthy diet (Leventhal et al., 1992). Interestingly, a recent qualitative study found that some cancer survivors do not engage in health behaviours because they do not accept the link between health behaviours and cancer (Corbett et al., 2018). Meanwhile, other survivors accept this link but report barriers to engage in a healthy lifestyle (Corbett et al., 2018). Further investigations are required to examine cancer survivors' beliefs regarding the use of physical activity and fruit and vegetable intake to reduce the risk of cancer recurrence.

Revised Common-Sense Model

As previously described, the CSM was chosen for this study as it is the most comprehensive and empirically validated model applied to FCR (Fardell et al., 2016). Additionally, the model was developed to predict health behaviours in chronically ill patients (Leventhal et al., 1992). Interestingly, a recent exhaustive literature review and meta-analysis of studies applying the CSM across chronically ill patients concluded the relationship among CSM constructs is more complex than initially described (Hagger, Koch, Chatzisarantis, & Orbell, 2017). Using empirical data, the authors revised the CSM to demonstrate emerging relationships among components of the model. Interestingly, some of the suggested paths were also identified

in this thesis. To remain succinct, only the relationships relevant to the scope of this thesis will be discussed.

Direct effects of illness representation on outcomes. There is evidence that coping accounts for only part of the effect of illness representation on outcomes, and that there exist direct effects of illness representation attributes on outcomes (Hagger et al., 2017). In this thesis, the direct relationship between timeline and FCR (outcome) across the three FCR severity models further supports this finding. Moreover, in the high FCR group, control over health also emerged as a direct indicator of FCR. Interestingly, these paths were added to the original model in the path analysis and the results suggest that some illness representation attributes have a direct effect on FCR without accounting for coping.

Furthermore, Hagger et al., suggests trends within these direct relationships with consequences and identity attributes positively predicting maladaptive outcomes (i.e., greater distress, poorer well-being) and perceived control as a positive predictor of adaptive outcomes (better functioning and less distress). In our sample, the results showed that a greater perceived chronicity of cancer had a direct positive effect on FCR severity across the FCR severity groups. This highlights the direct effect of a poor illness representation on maladaptive emotional outcomes.

In contrast, survivors in the high FCR group, who perceived less control over their health reported less FCR severity (direct relationship). This is opposite to the expected outcomes, as perceived control is generally predictive of direct adaptive outcomes (Hagger et al., 2017). Given that this relationship is specific to the high FCR group, this suggests that there may be a mediating factor not accounted for in the model influencing the direct effect of control over health on FCR outcomes. In fact, there is emerging evidence of the extraneous mediating

variables, for example, the "all or nothing" coping style often adopted by chronically ill individuals, who cycle between full engagement in coping behaviours to manage illness outcomes, and then complete disengagement (Hagger et al., 2017). Interestingly, this coping style is particularly prevalent in patients susceptible to distress and who have perfectionistic traits (Limburg, Watson, Hagger, & Egan, 2017). Hence, cancer survivors in the high FCR group might be influenced by extraneous factors, such as coping style, which would explain why their perceived level of control predict negative FCR outcomes.

Indirect effect of illness representation on outcomes through coping. In its original formulation, Leventhal suggested that illness representation indirectly predicted specific outcomes through a coping response (Leventhal et al., 1992). However, there is emerging evidence that illness representation attributes have both positive and negative indirect effects on outcomes, suggesting that the constellation of patterns among CSM components are more complex than originally thought (Hagger et al., 2017). For example, illness representation attributes have been shown to activate multiple coping responses that led to adaptive and maladaptive outcomes. This is relevant to this thesis as it could be another explanation for the opposing findings in the high FCR group, where high control over health concurrently predicted higher FCR (direct relationship) and lower FCR (indirectly through health behaviours and self-efficacy to manage health). Perhaps control over health led to two coping responses: the first being adaptive coping through problem-focused coping (engaging in physical activity and fruit and vegetable intake) predicting lower FCR and; second, maladaptive coping, potentially avoidance, which is commonly seen in this sub-group of cancer survivors, leading to higher FCR.

Moreover, Hagger et al. (2017) suggested that circumstances might motivate patients to

engage in these distinct coping responses. It is therefore crucial to consider these circumstances to accurately predict the selection of coping response by survivors and its subsequent impact on outcomes. The authors argue that interventions should not only target the illness representation attributes but also consider the resulting coping response(s) that may lead to adaptive and/or maladaptive outcomes. For example, interventions that highlight the seriousness of illness consequences might lead to adaptive problem-focused coping but in turn increase maladaptive outcomes such as increased distress.

Likewise, as seen in this thesis, a positive illness identity and fewer consequences predicted an increase in physical activity and greater self-efficacy to manage health across FCR severity groups. However, targeting illness identity & consequences is expected to lower FCR only in the low and high FCR groups, given that appraisal of health behaviour efficacy was predictive of FCR in these two groups. This highlights the importance of considering FCR severity sub-groups when selecting interventions, as targeting an illness representation attribute may lead to distinct outcomes.

Another illness attribute that yielded distinct outcomes is timeline. As suggested by the thesis findings, reducing the perceived chronicity of cancer (timeline) could lead to a decrease in FCR severity across FCR groups. However, given the distinct relationship between timeline and physical activity across FCR groups, targeting timeline may be unrelated to physical activity in survivors with low FCR, increase physical activity in survivors with moderate FCR, and reduce physical activity in survivors with high FCR.

This re-iterates the importance of considering multiple direct, and indirect effects of illness attributes on outcomes, as well as other pertinent circumstances such as FCR severity subgroup. The CSM framework was helpful to explore the relationship between FCR and health

behaviours as it is the only model that explicitly integrates these two constructs.

Limitations

This thesis had many strengths such as a combined longitudinal design spanning from early to long term survivorship, and cross-sectional design integrating a robust theory to explore empirical data. It was also one of the first studies to use a statistical method to cluster survivors based on their FCR scores overtime and further analyse relevant survivorship factors by FCR severity groups. If all cancer survivors were grouped in one entity, the yielded results would be inaccurate for sub-groups of cancer survivors. With that said, the study had some limitations which will be discussed in the following section.

Sample. While the ACS developed a protocol to obtain an optimal sample of American cancer survivors, individuals who completed the questionnaire packages have specific characteristics, such as being female and higher education (Smith et al., 2007). Moreover, only a sub-sample of participants completed all three SCS-I questionnaire packages limiting this sample and creating a less diverse cohort of survivors. To assess this limitation an analysis of missing pattern was conducted while selecting the thesis sample. To determine if attrition was random, the socio-demographic and medical variables of the selected thesis sample and the eliminated sample were compared using T-tests and Chi-squares. In the instance that group differences were identified, effect sizes (Cohen's D for T-test and ϕ for chi-squares) were calculated. The Cohen's guidelines to interpret magnitude of effect were used, where effect size is small if $d = 0.2$ or $\phi = 0.1$, medium if $d = 0.5$ or $\phi = 0.3$, and large if $d = 0.8$ or $\phi = 0.5$ (Cohen, 1992).

Results showed that samples differed for age at a diagnosis, $t = -11.64$, $p < .00$, $d = 0.32$; time since diagnosis, $t = -7.13$, $p < .00$, $d = 0.19$; education, $\chi^2 = 176.55$, $p < .00$, $\phi = .174$; sex, $\chi^2 = 9.826$, $p = .002$, $\phi = .041$; ethnicity, $\chi^2 = 70.685$, $p < .00$, $\phi = .110$ and cancer site, $\chi^2 = 231.131$,

$p < .00$, $\phi = .198$. While groups differed for six patient variables, the effect size was small for five of these variables. Meanwhile, the age at diagnosis had a medium effect size, where the thesis sample were on average four years younger than the eliminated sample (thesis sample $M = 56.2$ years, eliminated sample, $M = 60.1$ years). Therefore, attrition was non-random, but the differences between the thesis sample and eliminated sample are generally within a small magnitude.

The data is also susceptible to survivorship bias, given the probability that some participants did not respond to the second and/or third survey due to severity of illness or being deceased. Unfortunately, these cancer patients who may have particular characteristics, behaviours, or responses to survivorship variables were excluded in the study.

Timing and interval of data collection. Another important consideration is the time of data collection. Data collection began in the early 2000's and health behaviours, particularly physical activity, were only formally recommended in America starting in 2003 (Kushi et al., 2012). Therefore, uptake of these behaviours in response to recommendations may be delayed. Nevertheless, there was no significant change in physical activity at time 3 even though the guidelines had been published for several years. Moreover, adherence rates for physical activity and fruit and vegetable intake in this sample were similar to rates measured in the last few years (Bluethmann et al., 2015; Brunet et al., 2014; Hawkins et al., 2017; LeMasters et al., 2014).

The interval of time between data collection was inconsistent for all participants. Given that time was the independent variable in the FCR clustering analysis, this posits an important limitation. While it would have been ideal to have a more consistent timeline, this limitation was deemed tolerable given that the three time points each represented an important stage of cancer survivorship; re-entry (before 2 years post-diagnosis), early survivorship (between 2-5 years

post-diagnosis), and long term survivorship (5 years post-diagnosis and beyond) (Stanton, Rowland, & Ganz, 2015). Therefore, in the data interpretation the emphasis was on the stage of progression overtime instead of specific time intervals between data points.

Measurement tools. Given that this thesis was a secondary analysis of data, measurement tools were selected prior to the elaboration of the study protocols. The questionnaire packages were not designed for the thesis research design and hypotheses, instead the development of the study design was a negotiation between research objectives and available data. Given the large cohort of cancer survivors, the strong psychometric properties of the measurement tools in the surveys and the longitudinal nature of the data, it was deemed preferable to work with this rich data set rather than conduct a new data collection. Hence, the thesis had a few measurement limitations due to secondary use of data.

In the first questionnaire package, administered in early 2000's, current gold standard measures were not yet available, therefore they were only included in subsequent time points. This was particularly important for FCR, measured at all three timepoints with the Cancer Problems in Living Scales (CIPLS) -FCR subscale (Baker, Denniston, Zabora, & Marcellus, 2003), recognized as an adequate FCR measure (Thewes et al., 2012), but not the gold standard. It was only at time 3 that the Fear of Cancer Recurrence Inventory -Severity subscale (FCRI-s), the current gold standard measure of FCR (Simard & Savard, 2009; Thewes et al., 2012) was administered. Therefore, the ACS SCS-I questionnaire packages were modified overtime which in some respects is beneficial as it reflected the most up to date measurement tools, but this is also a disadvantage because the measured constructs changed overtime which limits ability to compare scores across time. For example, physical activity and fruit and vegetable intake were only measured at time 2 and time 3, limiting the possibility of comparing adherence to health

behaviours across all three time points.

While these tools in the ACS SCS-I are psychometrically sound and valid measures of constructs, they differ from the questionnaires commonly used in the literature limiting generalizability. This was particularly relevant for the illness representation attributes, generally measured using the Revised Illness Perceptions Questionnaire (Moss-Morris et al., 2002). Moreover, one CSM component (perceived cause of cancer) was excluded from the study given that the construct was not included in the ACS SCS-I.

Finally, all measures used in this study are self-report questionnaires. Therefore, data is susceptible to the respondent's ability to recall and social desirability. This is particularly true for the measures of physical activity and fruit and vegetable intake as these health behaviours were not objectively observed and relied on participant's subjective measure of their habits. Despite this, the LTEQ and the 5-a-day measures have been shown to be reliable indicators of health behaviours (Smith et al., 2007).

Statistical Analysis. In study 1, FCR was measured at three time points, with the first two survey administrations closer in time, in early survivorship, and the third later in cancer survivorship. Statistically, this means that the potentially observable trajectories are limited to linear or quadratic trends. However, it is possible that FCR fluctuates more frequently overtime, particularly between time 2 and time 3 given the length of the time span. Therefore, increasing the frequency of FCR assessment is warranted to confirm the trajectories observed in this study. The trajectory groups identified in this thesis are empirical in nature and while they reflect FCR severity, based on FCR measures, it remains unclear how these trajectory groups reflect clinical levels of FCR.

As previously mentioned, physical activity and fruit and vegetable intake were only

measured at time 2 and time 3, in the absence of measures at time 1 comparative analyses were limited to two time points. Furthermore, while repeated measures ANOVA enabled the comparison of health behaviours between time 2 and time 3 by FCR sub-groups, the relationship between FCR severity and health behaviours over time remains unclear and warrants further investigation.

Study 2 was limited by its cross-sectional design, capturing FCR and health behaviours only in long-term cancer survivorship. Factors in the CSM model have been shown to fluctuate in time (Leventhal, Phillips, & Burns, 2016), consequently, using a static measurement protocol is not representative of cancer survivors' responses across survivorship. Moreover, statistically, cross-sectional findings can only demonstrate the strength of a relationship between variables but not the direction of the relationship. Therefore, the interpretation of relationships between variables was extrapolated from the CSM theoretical framework, which has been empirically validated in cancer survivors.

The ACS data set obtained for the thesis was in composite scale scores format. Without access to the observed variables, assessing latent constructs was impossible. Hence, path analysis was chosen to examine FCR and health behaviours in the CSM. While using composite scores instead of latent variables might not allow for measurement modeling, path analysis was deemed acceptable given the strong empirical evidence of the CSM theoretical framework in cancer survivors (Fardell et al., 2016). It is also worthy to note that although the final models showed a good fit, most direct and indirect effects had a small effect size, except for the control-appraisal path yielding a medium effect size and the timeline-FCR path yielding a large effect size (Cohen, 1992). This means that while the model may help better understand the relationship between these survivorship variables, it can only account for part of the variability within the model.

Applicability of findings to the Canadian population. Given that the thesis was conducted using a sample of American cancer survivors, it is unclear if these findings are applicable to Canadian cancer survivors. Comparing the health behaviour guidelines for cancer patients published by the Canadian Cancer Society (CCS) and the American Cancer Society (ACS) are similar but slightly different. While the ACS recommends 150 minutes of moderate physical activity or 75 minutes of vigorous physical activity weekly (Kushi et al., 2012), the CCS recommends at least 30 minutes of moderate physical activity a day, corresponding to 210 minutes of moderate physical activity a week (Canadian Cancer Society, 2018). In terms of fruit and vegetable intake, the ACS recommends the intake of at least five portions of fruits and vegetables each day (Kushi et al., 2012), while the CCS offers vague recommendations stating that individuals should aim to increase their fruit and vegetable intake and that the number of servings every day depends on the individuals age, sex and activity level, with no further specifications (Canadian Cancer Society, 2018). It is possible that these distinct guidelines would yield different adherence rates.

When comparing Canadian and American health populations, access to health care is recognized as a fundamental difference between countries. In the United States cancer survivors may have inadequate health insurance coverage limiting accessibility to care meanwhile in Canada universal health care is offered to citizens. With that said, much like the United States, disparities in cancer care are also present in Canada with socio-economically disadvantaged groups, rural communities and ethnic minorities being under-served (Ahmed & Shahid, 2012). This type of inequity in cancer care is an important barrier to adopting a healthy lifestyle. Whether the proportion of cancer survivors affected by these factors differ between American and Canadian is unclear. Therefore, thesis findings may apply to a sub-group of Canadian cancer

survivors, particularly middle to upper class Caucasian individuals given the over-representation of this group in the thesis sample.

Clinical Implications and Future Directions

Screening for FCR. The thesis findings highlight the importance of screening for FCR severity in cancer survivors as subgroups of cancer survivors with moderate and high FCR will experience chronic levels of FCR. Moreover, the identified socio-demographic and medical characteristics of these cancer survivors (younger, female, of Hispanic ethnicity, diagnosed with advanced cancer stage and with NHL) may inform screening practices to identify patients at greater risk of high FCR severity. This could also be helpful to identify survivors at risk of experiencing moderate FCR (women diagnosed with breast or ovarian cancers) and those who may experience low FCR (older men, diagnosed with early cancer stage prostate cancer). Given the impact of FCR on cancer survivors' well-being and quality of life (Simard et al., 2013), future investigations should study the implementation of a routine screening instrument to measure FCR severity in clinical settings. Ideally, this type of screening could be conducted in a timely fashion by various health care professionals within the cancer care team. This could be the first step in a stepped care model to assess cancer survivors needs and inform subsequent treatment plans tailored by FCR severity. Given the distinct characteristics and manifestation of survivorship variables and outcomes in FCR sub-groups, using a stepped care model could be an adequate way to coordinate care benefiting cancer survivors, health care providers and health care systems.

Recognizing FCR severity is also important for health behaviour interventions. While engaging in physical activity and fruit and vegetable intake weakly influenced FCR only in patients with low FCR, CSM components predicting health behaviour practice varied by FCR

severity groups. Moreover, there was an emerging trend of cancer survivors with high FCR reporting less physical activity and fruit and vegetable intake. These findings suggest that FCR and health behaviour interventions should be tailored by FCR severity. Continuing with the idea of a stepped care model, the following are potential clinical implications based on thesis findings.

Stepped care model. Subsequent to the first screening step, survivors could benefit from health behaviour interventions targeting beliefs concerning the usefulness of health behaviours to manage cancer risk, increasing perceived control over health and subsequent self-efficacy to manage health (Corbett et al., 2018). Interventions should address disparities in practice of health behaviours, as survivors are more likely to engage in physical activity than consume fruit and vegetables. This second step may be sufficient for cancer survivors with low FCR, if the health behaviour interventions help increase physical activity and fruit and vegetable intake, they are expected to also maintain or reduce FCR. The second care step is likely insufficient for survivors with moderate and high FCR. While it may help increase health behaviour adherence in survivors with moderate FCR, it is not expected to reduce FCR severity.

In turn, survivors with high FCR are expected to have limited gains from health behaviour interventions given high distress levels and preoccupation, impacting their ability to adhere to healthy lifestyles (Mutsaers et al., 2016). Moreover, clinicians should be attuned to cancer survivors' perceived control over their health, given that this factor could be predicting two distinct responses to FCR: excessive coping or avoiding (Thewes et al., 2015). In this case, health care providers could tailor their approach when communicating health behaviour recommendations to better suit survivors' coping style. Hence, it is unclear what type of health behaviour intervention may be beneficial for cancer survivors with high FCR. Future studies

should aim at identifying optimal ways of promoting health behaviours within this sub-group. Bearing in mind, prior managing of FCR might be required to any successful health behaviour interventions.

As shown in this thesis, the CSM showed a good fit across participants, further supporting the use of the CSM in current FCR conceptualizations (Fardell et al., 2016; Lebel et al., 2014; Simonelli et al., 2017) and interventions (Butow et al., 2017; Lebel et al., 2014; Maheu et al., 2016). Therefore, as a third step in the care model, cancer survivors with moderate and high FCR could benefit from FCR interventions to help them cope with FCR. As suggested by the thesis findings, targeting the perceived chronicity of cancer recurrence may help cancer patients manage their FCR. However, it is important to consider the distinct models yielded for the moderate and high FCR subgroups suggesting that interventions may require different ingredients for these two groups. Moreover, all current FCR interventions only target patients with high FCR severity (Butow et al., 2017; Lebel et al., 2014; van de Wal, Thewes, Gielissen, Speckens, & Prins, 2017). These interventions should be pilot tested to assess efficacy and determine if tailoring is required for survivors with moderate FCR.

Finally, as a fourth step in the care model, survivors with high FCR may require additional psychological support to manage higher levels of FCR. As suggested by the thesis findings, increasing cancer survivors' perceived competency to manage health could be an important FCR intervention target for this group. However, without the reduction of FCR levels we cannot expect this variable to predict adherence to health behaviours.

Conclusion

Overall, this thesis contributed to the examination of the relationship between FCR and health behaviours in cancer survivors across the survivorship trajectory. Although the practice of

health behaviours was only related to FCR in survivors with low FCR, relevant components of illness representation were found to predict FCR. Moreover, findings highlight the importance of considering FCR severity sub-groups when conducting psycho-oncology research and furthermore in clinical practice working with cancer patients.

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Appendix A- Questionnaires

Study 1 Measures

Sociodemographic Variables

1. What is your date of birth?

__-__-____
Month Day Year

2. What is your gender?

- Female
- Male

3. Were you born in the United States?

- Yes
- No If no, in what country were you born?

4. What describes your ethnic/racial background? *Mark all that apply.*

- African
- American/Black American
- Indian/Aleut/Eskimo
- Asian/Pacific Islander
- Caucasian/White
- Other (Specify): _____

5. Do you consider yourself to be of Latino or Hispanic origin or descent?

- Yes
- No

6. What is your current marital status?

- Married
- Living in a marriage-like relationship
- Divorced
- Separated
- Widowed
- Single, never married

7. What is the **highest** grade or level of education you have completed? *Mark only one.*

- 8th grade or less
- Some high school (grade 9 to 12)
- High school diploma or GED
- Vocational school or some college
- College degree
- Professional or graduate school experience

8. Are you currently living in a nursing home or other group care facility (this does not include living with family members who take care of you)?
- Yes
 - No
9. Including income provided by you, your spouse/partner and others you regard as family who live in your household, what was your total household income (from all sources) before taxes in the last calendar year?
- Less than \$5,000
 - \$5,000 - \$9,999
 - \$10,000 - \$19,999
 - \$20,000 - \$39,999
 - \$40,000 - \$74,999
 - \$75,000 or more
 - Prefer not to answer

Medical Variables

- 10.
- a. Please indicate which of the following types of cancer you have been diagnosed with **during the past 2 years. Mark all that apply:**
- Bladder
 - Breast
 - Colon or rectal
 - Kidney
 - Lung
 - Melanoma of the skin
 - Non-Hodgkin's Lymphoma
 - Ovarian
 - Prostate
 - Uterine (Endometrial)
 - Other type of cancer (specify): _____
- b. Date (month/year) of **most recent diagnosis:**
- - - - -

11. Did you receive treatment for your **most recently diagnosed cancer**?

- No
- Yes If yes, mark all the treatments that you received. Then for each treatment that you received, mark yes or no to indicate whether you have completed or stopped that treatment.

	Treatments received	Have you completed or stopped this treatment?	
		Yes	No
Surgery:			
• to remove the cancer	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
• other surgery (e.g., breast reconstruction, colostomy)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Chemotherapy	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Radiation Treatment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Bone Marrow Transplantation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Hormonal Therapy:			
• to reduce or shrink the cancer (e.g., Tamoxifen, Depo, Lupron, Flutamide)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
• to prevent another cancer (e.g., Tamoxifen)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Immunotherapy (e.g., antibodies, IGG, BCG, Interferon, Interlukin)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Other (specify): _____	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Study 2 Measures

Medical Outcomes Study Short Form (MOS SF-12)

15. In general, would you say your health is:

- | | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Excellent | Very Good | Good | Fair | Poor |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

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

- | | Yes, limited a
lot | Yes, limited a
little | No, not limited
at all |
|------------------------------------------------------------------------------------------------------------|-----------------------|--------------------------|---------------------------|
| a) Moderate activities , such as moving a table, pushing a vacuum cleaner, bowling, or playing golf | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b) Climbing several flights of stairs | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

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

- | | All of
the time | Most of
the time | Some of
the time | A little
of the
time | None of
the time |
|-------------------------------------------------------------|-----------------------|-----------------------|-----------------------|----------------------------|-----------------------|
| Accomplished less than you would like | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| Were limited in the kind of work or other activities | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

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

- | | All of
the time | Most of
the time | Some of
the time | A little
of the
time | None of
the time |
|-----------------------------------------------------|-----------------------|-----------------------|-----------------------|----------------------------|-----------------------|
| a) Accomplished less than you would like | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |
| b) Did work or activities less carefully than usual | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

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

- | | | | | |
|-----------------------|-----------------------|-----------------------|-----------------------|-----------------------|
| Not at all | A little
bit | Moderately | Quite a bit | Extremely |
| <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> | <input type="radio"/> |

20. These questions are about how you feel and how things have been with you during the

past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks...

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
a) Have you felt calm and peaceful?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b) Did you have a lot of energy?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c) Have you felt downhearted and depressed?	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

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

All of the time	Most of the time	Some of the time	A little of the time	None of the time
<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Perceived Barriers to Health Behaviours

22. The following statements are about exercise and nutrition. Please indicate to what degree you generally agree or disagree with each statement.

	Strongly disagree	Disagree	Neutral	Strongly Agree	Agree
a) I am physically unable to exercise.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b) I am embarrassed when I exercise.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c) There is no place I can exercise in my neighborhood.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d) Exercise will help me avoid getting cancer again.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e) Exercise will help me avoid getting a major disease other than cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f) Healthy foods do not taste good.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g) Eating healthy foods will help me avoid getting cancer again.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h) Eating healthy foods will help me avoid getting a major disease other than cancer.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
i) Exercise or grocery shopping for healthy food takes too much time.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
j) I cannot afford to buy healthy foods or a gym membership.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
k) Hours of grocery stores or gyms do not fit my daily schedule.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Revised Health Belief Model Scale – Susceptibility subscale

23. The following statements are cancer and cancer screening tests. Please indicate to what degree you generally agree or disagree with each statement.

	Strongly disagree	Disagree	Neutral	Strongly Agree	Agree
a) It is likely that I will get cancer again	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b) My chances of getting cancer again in the next few years are great	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c) I feel I will get cancer again sometime during my life	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Perceived Health Competence Scale (PHCS)

24. Please indicate how much you generally agree or disagree with each item below.

	Strongly disagree	Disagree	Neutral	Strongly Agree	Agree
a) I handle myself well with respect to my health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b) No matter how hard I try, my health just doesn't turn out the way I would like.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c) It is difficult for me to find effective solutions to the health problems that come my way.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d) I succeed in the projects I undertake to improve my health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e) I'm generally able to accomplish my goals with respect to my health.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f) I find my efforts to change things I don't like about my health are ineffective.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
g) Typically, my plans for my health don't work out well.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
h) I am able to do things for my health as well as most other people.	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Fear of Cancer Recurrence Inventory-Severity subscale

25. Many people who have been diagnosed with cancer are worried that there might be a possibility that the cancer could return or progress in the same place or in another part of their body (i.e., cancer recurrence). Please indicate to what degree each statement has applied to you during the past 4 weeks.

	Not at all	A little	Some- what	A lot	A great deal
a) I am worried or anxious about the possibility of cancer recurrence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
b) I am afraid of cancer recurrence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
c) I believe it is normal to be worried or anxious about the possibility of cancer recurrence	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
d) When I think about the possibility of cancer recurrence, this triggers other unpleasant thoughts or images (such as death, suffering, the consequences for my family)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
e) I believe that I am cured and that the cancer will not come back	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
f) In your opinion, are you at risk of having a cancer recurrence?					
Not at all at risk	<input type="radio"/>	A little at risk	<input type="radio"/>	Somewhat at risk	<input type="radio"/>
				A lot at risk	<input type="radio"/>
					A great deal at risk
					<input type="radio"/>
g) How often do you think about the possibility of cancer recurrence?					
Never	<input type="radio"/>	A few times a month	<input type="radio"/>	A few times a week	<input type="radio"/>
				A few times a day	<input type="radio"/>
					Several times a day
					<input type="radio"/>
h) How much time per day do you spend thinking about the possibility of cancer recurrence?					
I don't think about it	<input type="radio"/>	A few seconds	<input type="radio"/>	A few minutes	<input type="radio"/>
				A few hours	<input type="radio"/>
					Several Hours
					<input type="radio"/>
i) How long have you been thinking about the possibility of cancer recurrence?					
I don't think about it	<input type="radio"/>	A few weeks	<input type="radio"/>	A few months	<input type="radio"/>
				A few years	<input type="radio"/>
					Several years
					<input type="radio"/>