

CAUSAL ATTRIBUTIONS, COPING STRATEGIES, AND FEAR OF RECURRENCE IN
LYMPHOMA SURVIVORS.

by

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ABSTRACT OF THE DISSERTATION

Causal Attributions, Coping Strategies and Fear of Recurrence in Lymphoma Survivors.

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Survivorship is defined as the period between termination of active cancer treatment and recurrence or death. With early detection, treatment advances, and an aging population, the number of cancer survivors is quickly increasing. Amongst survivors a common, chronic, and burdensome challenge is managing fear of cancer recurrence (FCR), worry that cancer will return. The current study examined the relationship between important factors of adjustment in survivorship, causal attributions, coping strategies, and FCR. Data was collected for a lymphoma survivorship trial at four major cancer centers (N=142). Standardized measures were collected at baseline, six and 12-months, in combination with a qualitative interview at six-months. Consistent with hypotheses that modifiable causal attributions suggest targets for control, survivors who identified modifiable causes of cancer reported significantly more total coping strategies, and more coping directly aligned with the cause. FCR significantly decreased from baseline to 12-month follow-up. As hypothesized, high levels of FCR at baseline were associated with higher reported coping at six-months. Additionally, evidence suggested that across all time points FCR was greater in those with high total coping reported at six-months. However, the study did not find that reported coping at six-months was associated with a reduction in FCR over time. Finally, post hoc analysis revealed key differences in coping and the relationship with FCR over time for those who attributed stress as the cause of their cancer. This study contributes

to the growing literature on cancer survivorship and deepens our understanding of FCR, coping, and causal attributions. These findings have important implications for understanding how cancer survivors view cause of their illness and how cause relates to coping. Lastly, this study adds to the current understanding of the relationship between FCR and coping in early survivorship.

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Introduction

The current study investigated the relationships of key factors of adjustment in cancer survivorship. Specifically, the study examines Lymphoma survivors and the relationship between causal attributions (identified cause of illness) and reported coping strategies, and the relationship between reported coping and FCR overtime. The importance of survivorship research is clear as the number of cancer survivors is quickly increasing with early detection, treatment advances, and an aging population. Within the United States population, 4.8% (15.5 million) are cancer survivors (Bluethmann, Mariotto & Rowland, 2016); survivorship defined as the period between active cancer treatment and recurrence or death. This number is estimated to increase to 20.3 million by 2026 (Bluethmann, Mariotto & Rowland, 2016). The most commonly reported unmet need of survivorship is managing fear of cancer recurrence (FCR) (Simard et al., 2013), a burdensome and potentially chronic worry that cancer will return, either in the same or different location (Vickburg et al., 2003). For survivors, the transition from active treatment can feel abrupt and unsettling as survivors attempt to resume their typical pre cancer way of life, and are faced with how to manage FCR.

A Vulnerable Time: Transition to Survivorship

Immediately following the termination of active cancer treatment a survivor will transition from weekly appointments that involve monitoring, social interaction, and reassurance from oncologists, to bi-annual follow-up appointments. The loss of professional oversight and monitoring by a healthcare professional, to self-examination provides an opening for activation of uncertainties about one's ability to detect recurrence. The change has been described as the "loss of a safety-net," requiring

individuals to monitor and respond intelligently to new health threats (Costanzo et al., 2011). Survivors have acknowledged the onset of FCR during this period. One breast cancer survivor noted, “I felt such a sense of security when I was going through radiation... You felt safe while you were going there, and now that you’re not ... you feel like something is going to happen” (Allen, Savadatti & Levy, 2009, p. 75). Given the growing number of survivors and the difficulties they face during this transition period, it is important to identify factors that play critical roles in adjustment, in order to develop interventions that target healthy survivorship.

How Survivors Make Sense of their Illness

The Common Sense Model. The Common Sense Model (CSM; Leventhal, Meyer & Nerenz, 1980; Leventhal, Phillips & Burns, 2016) provides a patient-centered conceptual framework for demonstrating how survivors represent, cope and manage both illness and emotional reactions during the transition from active treatment to self-management. Studies of multiple chronic conditions (e.g. Asthma, diabetes, and hypertension) have increased our understanding as to how people understand and cope with illness.

CSM models the ongoing feedback and feed forward processes among the following four components; the representation of the self, the illness (cancer), coping behaviors, and action plans for implementation in the local environment. Cognitive representations of an illness and possible treatments are formed and updated at multiple time points enriching the individual’s understanding of the disorder, his/her assessment of risk, and selection of tactics and strategies for risk management (i.e., coping). Five sets of attributions of representations of both illness and treatment are involved in the updating

process. The first is *illness identity*, the symptoms and functional changes perceived to mark the presence and changes in the disorder along with its verbal description (i.e., label as lymphoma). Secondly, *cause* is the experienced antecedents believed to have initiated the illness, this entails possible ideas and beliefs about how one contracted the illness and potentially stimulated developments in the illness, including the personality or behavioral causes of an illness (e.g. negative attitude, smoking, and stable factors such as genetics). *Consequences* are the experienced impact and beliefs about the effect of the cancer on one's life (e.g. social, economic, physical, and emotional). *Control* defines the individual's perception that the disease and its recurrence is manageable, and suggests links to the various procedures seen as effective in controlling the illness. This includes experiences reinforcing specific beliefs about how to control the symptoms, functional disruptions and progress of the lymphoma. *Timeline* is the experienced and expected time for the development/onset of the cancer and its likely duration (e.g., months, years, lifetime and life ending). It also includes the time frame for utilization of action (e.g., medication, life style change) to control the disorder (Leventhal, Phillips & Burns, 2016).

The expectations embedded in this multi-component bundle, the individuals representations of lymphoma and its treatment, describe the individuals understanding of the threat and the actions expected and believed necessary to ameliorate ongoing and to prevent threat and emotional distress. During the transition from active treatment to survivorship, illness representations shift, the threat of cancer is reexamined and different components of CSM will be active at different points in time.

Fear of Cancer Recurrence (FCR)- An Issue in Survivorship

FCR is a prevalent challenge among cancer survivors. During the transition from active treatment to survivorship where one switches from physician-dependence to self-reliance, worries about one's ability to control and detect recurrence are likely. A systematic review (k=130) by Simard and colleagues (2013) concluded that FCR is the most commonly reported unmet need among survivors. Across different cancers and measures, on average 73% of survivors reported FCR, and 49% of survivors asserted that it reached moderate to high levels. FCR can either be diffuse in nature or be specific to triggering events (i.e. Situation Specific Fear of Recurrence; SSFCR), such as annual scans or check-ups. Symptoms that are considered normal in early survivorship (e.g. fatigue, pain, effects of treatment) are present and often severe in early survivorship (Crist & Grunfeld, 2013); studies have shown that misinterpretation of physical symptoms that match the cancer prototype can evoke distress and FCR (Benyamini, Mclain, Leventhal, & Leventhal, 2003; Humphris & Ozakinci, 2008). Additionally, FCR can be triggered by an array of cues including external ones (e.g., a conversation about cancer, or walking by a cancer center), which activate memories and beliefs about cancer (Easterling & Leventhal, 1989).

Several studies reviewed found that FCR is constant, changing little over time (Crist & Grunfeld, 2013); persistence consistent with the evidence that recurrence in later years is high, particularly when it originated early in life (Koch et al, 2014). Furthermore, FCR has a significant impact on daily life and adjustment to survivorship, and has been shown to reduce quality of life (QOL), and increase distress, anxiety and depressive symptoms among cancer survivors (Koch et al, 2014; Simard et al., 2013). Due to its

prevalence, chronicity, and psychological consequences, FCR is an important target for research.

Causal Attributions: What Survivors Believe to be the Cause of their Cancer?

Causal attribution refers to the process in which people create theories about the cause of something (e.g. illness) in an effort to make sense of the world and what is happening (Kelley & Michela, 1980). Consistent with CSM, survivors are likely to have a variety of ideas about the cause of their cancer. Causes include perceptions and beliefs regarding the factors responsible for the onset and maintenance of cancer, including how it was contracted (smoking, diet, etc.), and factors responsible for one's vulnerabilities to these agents. Survivors are likely to review past histories: family, behavioral, exposure to toxins, to understand and guide action to avoid recurrence of the illness. Whether or not they are consistent with scientific knowledge about the illness, causal attributions are a key component of a person's understanding of his/her condition and provide the basis for self-selection of additional coping strategies.

Research has shown that causal attributions affect an individual's sense of control (Berkman & Austin, 1993) of cancer. For example, if one attributes their cancer to a specific modifiable cause(s) with a target for action, their sense of control may instigate coping towards that cause. Correspondingly, research supports that cancer survivors who identify modifiable causal attributions are more likely to make behavioral changes to target the believed cause of cancer (Costanzo, Lutgendorf, Bradley, Rose, & Anderson, 2005; Rabin & Pinto, 2006). Additionally, prior studies have shown that causal attributions are associated with improved QOL (Stewart et al., 2001) and psychological adjustment (e.g. positive affect, well-being, level of distress, social functioning) (Taylor,

Lichtman, & Wood, 1984) in survivorship. Overall, causal attributions are an important factor in survivorship as they help individuals make sense of their illness, have a sense of control, and take action towards the cause.

Strategies for Coping with Survivorship

Coping refers to strategies that can be cognitive or behavioral, which help people manage stress (Folkman & Moskowitz, 2004). As defined by the CSM, coping strategies are responses to address the perceived aspect of an illness threat or the individual's emotional reactions to the threat. For survivors, coping is a way of confronting threats of life and well-being, which plays an important role in adaptive survivorship.

Problem-focused coping refers to strategies that target specific sources of stress, while emotion-focused coping involves strategies that target subjective feelings and thoughts related to the stressor (Folkman & Lazarus 1980; 1985). A problem-focused cancer survivor might use sunscreen to reduce risk of skin cancer while an emotion-focused survivor engages in daily mindfulness practices to reduce worry about recurrence. Broadly, research supports an association with problem-focused coping and reduced psychological distress (i.e. Dempster et al., 2011; Costanzo et al., 2007; Deimling, Bowman, Sterns Wagner & Kahana, 2006) in survivorship. Additionally, research has shown that problem-focused strategies have been correlated with positive adjustment in survivorship (Stanton et al., 2000).

FCR, Causal Attributions, and Coping

Given that FCR, causal attributions, and coping are key factors in adjustment and healthy survivorship, it is important to investigate their relationship to one another.

Causal Attributions & Coping. Costanzo and colleagues (2011) found evidence that supports the interconnection between causal attributions and coping. Specifically, breast cancer survivors who attributed the cause of their cancer to poor health or stress (i.e. modifiable causes) were more likely to endorse efforts inline with targeting the identified cause (e.g. improvement in physical activity, diet, alcohol consumption, and stress). Consistent with the CSM, these examples are representative of causal beliefs affecting coping. Additional studies have shown that cancer survivors who identify modifiable causal attributions are more likely to make behavioral changes to target the believed cause of cancer (Costanzo, Lutgendorf, Bradley, Rose, & Anderson, 2005; Main et al., 2005; Rabin & Pinto, 2006). As exemplified by a survivor in a qualitative study by Main and colleagues (2005) reported, “there is always the memory of the cancer and what I believe the cause of the cancer was [stress], and it definitely motivates me ...” (p. 1000-1001). Franks & Roesch (2006) found that survivors who viewed their cancer as a continued threat were more likely to use problem-focused coping as compared to those who viewed their cancer as a harm or loss which were more likely to use avoidance coping strategies.

Coping Strategies & FCR. Research supports that coping mechanisms have been instigated in response to FCR (i.e. Allen, Savadatti & Levy, 2009, Hawkins et al., 2010; Mullens et al., 2004). Allen, Savadatti & Levy (2009) examined qualitative data of breast cancer survivors; and one common theme identified was that FCR prompts threat-reducing coping strategies. As a response to threat of recurrence, the majority of women in the study had implemented positive behavioral changes such as improvement in exercise, diet, and stress-reduction (Allen, Savadatti & Levy, 2009). Similarly, Hawkins

et al. (2010) showed that high FCR typically predicted positive behavior change (e.g. more frequent check-ups, and healthy diet). Additionally, although FCR was not specifically measured, Mullens et al. (2004) found that vulnerability, worry, and anxiety were associated with intent to engage in self-protective health behaviors (e.g. improve diet, weight loss, physical exercise). This evidence suggests that survivors could be responding to worry and specifically FCR by changing lifestyle in order to protect against health threats. Although these findings came from cross-sectional data they provide support that the perceived threat of cancer recurrence may motivate individuals to take action in order to protect themselves and reduce worry.

Furthermore, studies have shown an association between increased problem-focused coping and reduced psychological distress (i.e. Dempster et al., 2011; Costanzo et al., 2007; Deimling, Bowman, Sterns Wagner & Kahana, 2006; Stanton, Danoff-burg, & Huggins, 2002) in survivorship. Among esophageal cancer patients, Dempster and colleagues (2011) found that problem-focused strategies reduced psychological distress (e.g. symptoms of anxiety and depression) while strategies of relaxing, reflecting, and distractive-based coping (i.e. emotion-focused coping) were linked to more psychological distress. Similarly, research has found an association between more avoidance-based coping (e.g. denial) and higher levels of FCR (Cohen, 2002; Costanzo et al., 2007; Deimling, et al., 2006; Stanton, Danoff-burg, & Huggins, 2002; Wade, Nehmy & Koczwara, 2005). Additionally, greater problem-focused strategies have been correlated with positive adjustment in survivorship (Stanton et al., 2000). More research is needed in this area to elucidate the effects of different coping types (emotion versus problem-focused) on FCR.

An examination of published data suggests that there is an association of modifiable causal attributions and coping. Coping responses can be differentiated into responses focused on modifying features of the illness threat versus those focused on managing the emotional response itself. Problem-focused coping has been shown to reduce psychological distress while emotion-focused coping has been shown to increase FCR. Furthermore, evidence suggests that FCR possibly instigates coping. Evidence supports the interconnectedness of these variables, however, no study to our knowledge has investigated the relationship between causal attributions and coping and the effect of coping on FCR over time in lymphoma survivors.

The Current Study

The current study will examine survivors of Hodgkin Lymphoma (HL) and Diffuse large B-cell lymphoma (DLBCL) from termination of active treatment until 12-months into survivorship. Although DLBCL, a form of non-Hodgkin lymphoma, is more common than HL; the two have relatively similar treatments and high five-year survival rates (>90% for HL and >61% for DLBCL; American Cancer Society, 2017), making them an ideal population for investigating the relationship between causal attributions and coping strategies and the relationship between coping and FCR overtime. The current study adds to existing literature using longitudinal data in early survivorship to improve our understanding of factors that affect FCR following active treatment. Additionally, the study could provide valuable implications for potential illness representation-based interventions, which target a patients' understanding of cancer in order to aid in healthy long-term survivorship.

Aims and Hypotheses

Three sets of variables were assessed in a sample of individuals from four different cancer center sites who have recently completed treatment for HL or DLBCL: 1) The perceived causes of lymphoma (causal attributions); 2) Coping strategies (emotion-focused, problem-focused coping, total coping); and 3) FCR. The aims and hypotheses are as follows:

AIM I: Assess relationships among causal attributions and coping strategies, and examine whether survivors who identified modifiable causes:

I-H1: A) report more coping strategies overall.

B) report more problem-focused coping strategies.

C) connect cause with related coping responses.

AIM II: Examine the relationship between coping strategies and FCR at each point in time (baseline, six-months and 12-months post treatment):

II-H1: elevated FCR at baseline will be associated with higher numbers of coping strategies at six-months (see *Figure 1*).

II-H2: total coping strategies at six-months will be positively associated with a greater change (reduction) in FCR from baseline to 12-months, and six to 12-months.

II-H3: emotion-focused coping will not be related to changes in FCR over time.

Method

Study Design

The current study used data collected from a multi-site lymphoma survivorship trial (i.e. Parker et al., 2016). Patient recruitment occurred at four individual cancer centers across the United States: Memorial Sloan Kettering Cancer Center, Maimonides

Cancer Center, MD Anderson Cancer Center, and Moffitt Cancer Center. These centers were randomized to one of two arms, survivorship planning consultation (SPC; Intervention) or wellness rehabilitation consultation (WRC; Control). The study used a multiple-level cluster-randomized design. Thirty-six oncologists (18 per study arm) were recruited from lymphoma services at each site to participate in the study. They received a letter of introduction from the site PI and each service chief, and engaged in individual discussions about the costs and benefits of participating in the study.

Lymphoma survivors were recruited from clinics at each site. Inclusion criteria involved: 1) diagnosis of HL or DLBCL, 2) complete remission after the conclusion of chemotherapy, immunotherapy and/or radiation therapy, 3) at least 18 years old, 4) English speaking, 5) informed consent (approved by site-specific IRB). Exclusion criteria included: 1) cognitive impairment, 2) prognosis or comorbidities which would make them inappropriate for the study (as per physicians judgment).

Eligible participants were asked to fill out questionnaires following their initial visit, schedule a consultation, survivorship planning or wellness rehabilitation (15 minutes), and to complete additional measures at three, six, nine and 12-month follow-up appointments. Meetings with participants were audio recorded and target behaviors were coded to ensure fidelity throughout the study. If less than 80% of the protocol specific behaviors were completed, the oncologist was contacted by study investigators to provide feedback and reinforce skills. For complete details see Parker et al., 2016

Participants

A total of 184 of the 201 survivors screened were eligible for participation in the intervention; 120 consented and 119 completed the baseline assessment (59% of total

screened). One hundred participants were screened and eligible for the control arm, 81 consented and 80 completed the baseline assessment (80% of total screened; see Table 1 for participants per site and time point). At 12 months, 71 patients (36%) of the total sample are missing the assessment. The sample was predominately female (51%), Caucasian (54%), married (43%), and employed (40%). Racial minorities made up 28% of the sample with 9% identifying as Black, 7% Asian, 7% White/Hispanic, 4% Hispanic, and 1% other. The average age for the sample was 45.8 years of age (SD=17.7). Please see Table 1 and 2 for details regarding the sample.

Content of Trial Arms

Survivorship Planning Consultation (SPC). Oncologists in the SPC arm completed a five-hour Communication Skills Training (CST) workshop, which included: information about lymphoma survivorship; exemplary videos of recommended communication strategies in a survivorship consultation; survivorship-themed role-plays with standardized patients (trained actors); and a discussion about the benefits and barriers to SPC implementation (Banerjee et al., 2015). Included in the intervention is a component where survivors discuss transitioning to survivorship with their oncologists, which includes an individualized care plan. The oncologist covers: (1) how to use of survivorship care plan, (2) disease and treatment details, (3) discusses long-term effects, (4) possible late effects, (5) specific physician recommendations, (6) additional health maintenance recommendations, and (7) discusses a number of social issues discussion (regarding return to work, housing, financial, and relationship issues) (Banerjee et al., 2015).

Wellness Rehabilitation Consultation (WRC). Oncologists in the WRC arm (control) completed a 2-hour training that focused on lifestyle and wellness with details on nutrition and exercise. Included in the control arm survivors and their oncologists 1) discuss the remission results, 2) if appropriate, conduct a physical examination, 3) provide patient with healthy nutrition hand-out and discuss the benefits, 4) provide patient with an exercise sheet guide, and discuss a walking program, 5) welcome questions and provide answers, 6) discuss and review medications as needed, 7) welcome patient to get in touch as needed, and 8) schedule a 3-month follow-up.

Specific to the current study, both arms included components related to coping strategies. Specifically, in the SPC arm the oncologist discussed health maintenance recommendations, which may include coping strategies such as diet, exercise, as well as other strategies more specific to the individual's health (i.e. specific physician recommendations). Additionally, in the WRC arm the oncologist discusses handouts related to diet and exercise. The distinct difference between arms related to coping strategies is the level of individualized information delivered by the oncologist (e.g. SPC: individualized recommendations provided; WRC: healthy nutrition and exercise handouts were discussed).

Measures

Fifteen measures were collected at varied time points to explore patient outcome data (see Parker et al., 2016 complete details of methods). For the purpose of the current study we used the six-month Qualitative Interview (QI), and a measure of FCR adapted from the Cancer Worry Inventory (CWI; D'errico, Galassi, Schanberg & Ware, 2000) at baseline, six months, and 12-months.

Qualitative Interview (QI). The interview comprised 21 open-ended questions, to assess key elements of survivorship through a CSM framework. Themes of questions included employment, daily living, barriers of survivorship, activities pre and post-cancer treatment, worry about cancer recurrence, and strategies for wellness. Sample items include: “What thoughts do you have about the possible causes of your lymphoma” and “In looking to your future health, what are the regular things you plan to do to optimize your wellness in the future?” See Appendix A for all questions.

FCR. For the current study, four items were selected from the *Cancer Worry Inventory* (CWI; D'errico, Galassi, Schanberg & Ware, 2000) to assess FCR at baseline, six-months, and 12-months. The CWI is a 24-item measure assessing five different factors of cancer worry including: death, burden, spirituality, chemotherapy, and treatment. The factor concerning fear of death (Cronbach's $\alpha = .92$; D'errico, Galassi, Schanberg & Ware, 2000) was selected based on the relevance to the FCR construct. Participants were asked to use a five-point scale from 0=none to 4=very much to answer, “How much did you worry about each of the following in the last seven days?” Four of the five questions from the factor were used to create the FCR variable, which included: 1) If I will die from this illness; 2) The cancer will spread; 3) Treatment will not get all of the cancer; 4) The cancer will come back. The fifth question from the factor “when I will die” was removed for the purpose of this study because it was not specific to cancer recurrence. For the adapted FCR measure reliability analysis revealed a Cronbach's α above .70 at all three time points (baseline: $\alpha = .825$; six-months: $\alpha = .868$; 12-months: $\alpha = .867$).

Preliminary Data Analysis

Coding Qualitative Data

Initially, audio recordings of the six-month interviews were transcribed. Secondly, the transcribed qualitative data was coded (preliminary coding details for the specific variables can be found at Appendix C). The data was broken up into four sections. Teams of two coders each received extensive training (two days, eight hours total). Both coders in each team independently coded the entire section of data, and it was crosschecked for reliability within teams.

Causal Attributions

Categories for fixed and modifiable causal attributions of lymphoma were adapted from Ferucci et al. (2011) (see Appendix D for coding scheme; see Appendix E for possible causes of Lymphoma.) The responses from QI #10: “What thoughts do you have about the possible causes of your lymphoma?” were coded into 1) fixed only (e.g. genetics, age, previous illnesses); 2) modifiable only (e.g. diet, alcohol use, etc.); 3) uncertain, (e.g., “I don’t know,” “not sure”); and 4) combined (i.e., both fixed and modifiable causes). For this coding process, an initial coder completed all coding, and a second coded 20% of the data; kappa assessed inter-rater agreement. Initial discrepancies and ambiguities were discussed and re-rated separately by each until coders were in complete agreement for all cases.

Coping Strategies

Three questions from the QI elicited coping responses. Two questions assessed coping associated with worrying about cancer and its recurrence: QI #13: “What are some of the things you did (do) on your own to keep your worry [FCR] under control?”; QI #15a: “Does worry about recurrence help to motivate you to take preventative

measures? What are some of these preventive measures?” A third question focused on concrete actions to optimize overall health: QI #19: “In looking to your future health, what are the regular things you plan to do to optimize your wellness in the future?” Responses were coded into: a) type (e.g. emotion or problem-focused coping), and b) amount (i.e. number of strategies identified) (see Appendix F). The following categories were used for type of coping: 1) problem-focused coping (i.e. active strategies that target reducing or acting on the stressor), and 2) emotion-focused coping (i.e. strategies to control emotion and worry). Total coping strategies mentioned were totaled, and specific sums were created per type.

Causal-related Coping. Separate from problem and emotion-focused coping categories, additional coding was conducted in order to identify causal-related coping. Causal-related coping is when an identified cause matches up with an identified coping strategy (i.e. causal attribution of “weight,” paired with the coping strategy of “improve diet”). Although similar to problem-focused coping, these distinctions are specific to the cause identified. In order to make this distinction, causal attributions were coded into themes using a similar coding scheme to the adapted version of Ferucci et al. (2011) (see Appendix G). Separately coping was coded into themed categories (e.g. reduce alcohol, smoking cessation, modify diet; see Appendix H). In order to identify causal-related coping, a separate cause-level dataset was created. The dataset included a separate line for each possible identified cause, and separate variables for each possible coping strategy match, as indicated by respective coding schemes (see Appendix G, H & I). Then for each participant coping strategies responses were coded per type as Yes=1 or

No=0. Finally, the patient-level data and the cause level-data sets were used to calculate seized opportunities (i.e. cause-related coping).

Results

Initial Analyses

Coping. Problem and emotion-focused coping responses were elicited by three questions: QI questions 13, 15a, and 19 (QI #13: “What are some of the things you did (do) on your own to keep your worry [FCR] under control?”; QI #15a: “Does worry about recurrence help to motivate you to take preventative measures? What are some of these preventive measures?”; QI #19: “In looking to your future health, what are the regular things you plan to do to optimize your wellness in the future?”); repetitive responses were not counted. Participants reported an average of 4.90 different coping strategies, performing a greater number of problem-focused ($M=2.89$) than emotion-focused strategies ($M=2.01$).

Cause. The majority of participants (65.7%) identified at least one cause when asked, “What thoughts have you had about the possible causes of your lymphoma?” Of the 192 responses for 141 participants, genetics was the most frequently mentioned cause (11.5%), followed by stress (10.9%) (*Figure 2*). The largest portion of responses were coded as non-modifiable (30%); 22.1% were modifiable, 13.6% were combined (both non-modifiable and modifiable), 18.6% were uncertain, and 15.7% no cause.

FCR. At the six-month time point participants were asked, “Turning to worry about your lymphoma, how often do you worry that it might come back?” Ninety-one percent ($n=134$) reported worrying, of those, 23.9% worried in response to environmental cues (SSFCR; e.g. they worried in the context of upcoming medical visits), while the remaining 67.1% ranged from once a month to daily.

Coping was assessed for 141 respondents at the six-month QI and FCR was assessed at baseline, six-months and 12-months. Two respondents were eliminated due to missing QI data. Summary statistics are presented in Table 3.

Hypotheses Testing

Intervention vs. Control. Demographic differences between the intervention and control arm were examined. Between the two groups there were no significant differences. Additionally, a series of analyses were conducted to assess the impact of the intervention arm (intervention vs. control), on the dependent variables including coping and FCR. No significant relationships were found between intervention arm and control, and thus will not be discussed further.

Furthermore, a series of preliminary analyses were conducted to assess the impact of potentially confounding variables on the dependent variables. The additional potential confounds included age, gender, educational level, geographic location (northern sites vs. southern sites) and site size (larger sites vs. smaller sites). The dependent variables included the coping and FCR measures listed in Table 4. T-tests were used to assess relationships with dichotomous confounds (gender, geographic location and site size). Pearson correlations were used to assess relationships with age, and Spearman correlations were used to test relationships with education. No significant relationships were found for educational level, geographic location or site size.

Two gender differences were detected on the measures of coping (Table 4). Females reported more emotion-focused and more total coping strategies, than males. In addition, two small but significant relationships were found between age and problem-focused coping ($r = -.174, p = .039$) and with FCR at six-months ($r = .186, p = .046$),

indicating that younger respondents used more problem-focused coping and older participants were more fearful of cancer recurrence. Based on these results, gender was entered as a factor when testing coping hypotheses. Given the absence of interactions between gender and other independent variables gender was eliminated from further analyses that tested a single independent variable. Additionally, supplementary analyses involving problem-focused coping and FCR at six-months were conducted using age as a covariate, but are not reported since results did not differ from those not considering age as a factor.

Aim I-H1: Based on the assumption that modifiable causal attributions suggest specific targets for coping we predicted that those identifying modifiable causes as compared to fixed causes would: A) report more coping strategies overall, B) report more problem-focused coping strategies, and C) connect cause with related coping responses.

Analysis was run to test whether those who identified modifiable causes reported more coping strategies overall. Results indicated that for those who identified modifiable causes significantly more total coping strategies were reported as compared to those who identified fixed causal attributions (see Table 5); hypothesis I-1A was supported. Secondly, although those who attributed modifiable causes reported slightly more problem focused coping strategies, the difference did not achieve statistical significance (Table 5); hypothesis I-1B was not supported.

A post hoc analysis examined a post-hoc hypothesis that stress focused coping, originally classified as emotion focused (e.g. stress reduction strategies), might be conceptualized as problem focused if the respondent reported stress as a cause of cancer. Those who identified stress as the cause of their cancer (n=21) reported significantly

more emotion-focused and total focused coping strategies (but not problem-focused coping), as compared to those who did not identify stress as a cause of their cancer (see Table 6). Results were consistent with expectations that modifiable causal attributions suggest targets for control, as reflective of greater emotion-focused coping in the context of stress as a cause.

As hypothesized (1-1C) a high percentage (88%) of those who reported modifiable causes also reported using coping strategies directly related to the perceived causes they attributed to their cancer. This evidence supports Hypothesis I-1C.

Aim II-H1: We predicted that elevated FCR at baseline will be associated with higher numbers of coping strategies at six-months. Hypothesis II-1 was tested using a Pearson correlation between baseline FCR and the total number of coping strategies at six-months. A significant relationship was found ($r = .189, p = .035$), suggesting that Hypothesis II-1 is valid.

Aim II-H2: We anticipate that total coping strategies at six-months is positively associated with a greater reduction in FCR from baseline to 12-months, and six to 12-months. Slope analysis of baseline, six-months and 12-months FCR was examined (Table 7). Analysis shows that FCR decreases significantly across time ($p < .001$). *Figure 3* suggests that the difference between FCR averaged across all three time points is higher in those with high total coping reported at six-months; the difference is right at the level of statistical significance at ($p = .055$), and should be replicated by future studies. The interaction between FCR across time and total coping is not significant, meaning that FCR does not decrease more or less depending on the level of coping.

II-H3: We hypothesized that emotion-focused coping is not related to changes in FCR over time. Pearson correlations were computed using change scores (baseline-12-months, baseline to six-months, and six to 12-months). Correlations were not significant for emotion-focused coping; nor were they significant for problem-focused or total coping strategies at any time point (see Table 8).

Given the differences in coping explored previously in Table 6. Post hoc slope analysis was conducted in order to test differences in FCR over time between those who identified stress as a cause of their cancer (n=21), and those who did not (n=118). Slope analysis revealed significant reduction in FCR overtime for both the groups. A significant interaction was found (see Table 9 and Figure 4), such that the decrease in slope of FCR is significantly more pronounced in the group who mentioned stress as a cause of their cancer. Survivors who identified stress as a cause, started off with higher FCR at baseline and lower FCR at 12-months follow up than those who did not mention stress as a cause.

Discussion

The purpose of this study was to examine the relationship between important factors of adjustment in survivorship, causal attributions and coping strategies, and coping strategies and FCR over time. Data was collected from a four-site lymphoma survivorship trial (N=142), standardized measures collected at baseline, six-months, and 12-months, in combination with a qualitative interview at six-months. The first aim was to assess relationships among causal attributions and coping strategies, and examine whether survivors who identified modifiable causes differed in reported coping strategies.

The second aim was to examine the relationship between coping strategies and FCR at each point in time.

Relationship Between Causal Attribution and Coping Strategies

Similar to previous research, the current study found that the majority of participants attributed a specific cause to their cancer (65.7%) (i.e., 78.4%; Ferrucci et al., 2011). Participants reported both fixed (e.g., genetics, previous medical conditions, etc.) and modifiable (e.g. diet, stress, etc.) causes consistent with findings across the ten most common cancers (Ferruci et al., 2011). Interestingly, participants reported a variety of causes, several of which were outside the scope of what research suggests for possible causes of HL and DLBCL, such as alcohol, smoking, and stress (American Cancer Society, 2017). These findings in the current study are consistent with previous research (i.e., Lord et al., 2012; Stewart, Duff, Wong, Melancon, & Cheung, 2001) that illustrates the inconsistencies of causal attributions and scientific knowledge. In contrast to previous breast cancer literature, lymphoma survivors did not attribute cause to psychological factors (e.g. deservedness, character blame, personality) (Ferruci et al., 2011; Hopman & Rijken, 2015). On average participants reported approximately five different coping strategies, slightly more of which were problem-focused than emotion-focused. Consistent with previous literature, females reported more emotion-focused and more total coping strategies than males (i.e. Matud, 2004).

In line with expectations, those who identified a modifiable cause reported significantly more total coping strategies, and more coping strategies that were directly aligned with taking action toward the identified cause. The latter is consistent with previous literature that cancer survivors who identify modifiable causes are more likely to

make behavioral changes targeting the perceived cause of cancer (Costanzo, Lutgendorf, Bradley, Rose, & Anderson, 2005; Rabin & Pinto, 2006).

Although those who attributed modifiable causes reported slightly more problem-focused coping strategies, the difference was not statistically significant. Post hoc analysis examined a post hoc hypothesis that stress focused coping, originally classified as emotion focused (e.g. stress reduction strategies), might be conceptualized as problem-focused if the respondent reported stress as a cause of cancer (i.e., problem-focused stress reduction coping to reduce stress in order to impact the cause specifically versus emotion focused coping to reduce stress and anxiety separate from the cause itself). Survivors who identified stress as a causal attribution reported significantly more emotion-focused coping and total focused coping strategies than those who did not identify stress as a cause of their cancer. These results were consistent with expectations that modifiable causal attributions suggest targets for control. The findings also give context to nonsignificant findings for Hypothesis I-1B, and identify a possible limitation within identifying problem and emotion-focused coping with respect to stress as a cause.

FCR overtime and Coping Strategies

The second aim was to examine the relationship between coping strategies and FCR over time. A systematic review by Simard et al. (2013) found that the majority (73%) of survivors with various cancer types reported FCR; similarly, the current study found that 91% reported experiencing FCR. The most common response was “only near medical checkups” (23.9%), showing that they experienced SSFCR specific to triggering events such as going to annual scans or check-ups. Similar to previous research, this suggests that concrete experiences (e.g. medical checkups) arouse worry (FCR)

particularly when people are symptomatic (Gill et al., 2004; Easterling & Leventhal, 1989). The current study found that FCR decreased significantly across time, however, previous research supports that FCR is relatively stable over time (Simard et al., 2013). In contrast, the time of survivorship in previous literature ranged from three months to six years as compared to the current study which used a 12-month follow-up.

The findings that a) greater FCR at baseline was associated with increased coping strategies reported at six-months, and b) FCR was higher at all time points in those with high total coping reported at six-months, are consistent with the hypothesis that FCR may instigate coping. This finding is correlational, as the current study did not capture baseline coping; however, it aligns with previous research (i.e. Allen, Savadatti & Levy, 2009, Hawkins et al., 2010; Mullens et al., 2004). These findings may suggest that those who are fearful are likely to engage in more coping strategies (i.e. Elmir, Jackson, Beale, & Schmied, 2010; Kvale, Meneses, Denmark-Wahnefried, Bakitas, & Ritchie, 2015), perhaps in an effort to assuage worry. Further research is needed to establish temporal precedence.

The current study did not find support that reported coping at six-months was associated with a significant reduction of FCR overtime. Given this finding, it is important to note that the most frequently reported experience of FCR was SSFCR (situation specific) and related to upcoming medical checkups or scans (i.e. “I worry only near medical checkups”). Thus if FCR is experienced more frequently surrounding the time when individuals have appointments (e.g., six and 12-months post treatment), we may see a spike in FCR for those individuals. It is possible that coping maybe effective in assuaging FCR as one goes about everyday life, but it may be less effective in reducing

FCR when one is facing the possibility of detecting a recurrence. Future studies should control for follow up appointments in relation to SSFCR, and gauge FCR at time points outside of medical follow-ups.

Post hoc analysis examined the difference in FCR overtime between those who identified stress as a cause and those who did not. Interestingly, findings revealed that the decrease in FCR was significantly more pronounced in the group who mentioned stress as a cause of their cancer. Survivors who identified stress as a cause, started off with higher FCR at baseline, and lower FCR at 12-months than those who did not mention stress as a cause. These findings are similar to those from Corter et al. (2012) who found that survivors who attributed their cancer to stress reported significantly higher levels of FCR. The authors suggested that perhaps those who indicated stress as the cause were more stressed and perhaps more worried. As is evidenced by these post hoc findings and Corter et al. (2012), future research would benefit from making a distinction between coping strategies specific to cause irrespective of coping type.

Limitations

The current study has several limitations. First, the findings may not be representative of survivors in general, as the oncologists treating the patients in the current study may have been more likely to discuss coping than would oncologists not involved in a trial. Another limitation was that the QI was not conducted at baseline, and thus coping and causal attributions were only assessed at the midpoint. This prevented the study from establishing temporal precedence between coping and FCR overtime. Additionally, this data is based on the assumption that coping and causal attributions stay the same overtime, which is unlikely the case. Future research would benefit from

replicating these findings in a representative sample outside of a trial, and examining coping at baseline and follow-up.

Although a strength of the study is the qualitative dataset which provides information on the diversity of individual causal attributions and coping strategies, a limitation was found in parsing out emotion and problem-focused coping in the context of stress as a causal attribution. In light of this challenge, post hoc analysis was conducted to investigate differences between those who attributed stress as a cause and those who did not. Future research could benefit from investigating the differences between these two groups in a larger sample.

Summary and Conclusions

The current study focused on lymphoma survivors during a vulnerable time of transition from end of treatment to 12-months post treatment. Findings revealed that those who identified a modifiable cause reported significantly more total coping strategies, and more coping strategies that were directly aligned with taking action toward the identified cause. Higher FCR at baseline was associated with higher reported coping at six-months. Additionally, evidence suggested that across all time points FCR was greater in those with high total coping reported at six-months. FCR decreased significantly over time, however no evidence was found to support that the decrease in FCR was related to expressed coping. Furthermore, post hoc analysis revealed key differences in coping for those who attributed stress as the cause of their cancer, and the relationship with FCR over time.

Despite limitations, the current study adds to existing literature using longitudinal data in early survivorship to shed light on causal attributions, coping, and FCR in the

context of lymphoma survivorship. These findings have important implications for understanding how cancer survivors identify cause of their illness, and how cause informs coping. It also adds to the current understanding of FCR and the impact of coping among early lymphoma survivors.

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Table 1. *Participants Per Site and Time Point.*

	MSKCC (Intervention)	Moffitt (Intervention)	MD Anderson (Control)	Maimonides (Control)	All
N	86	33	26	54	199
6 Months	67	21	19	32	139
12 Months	61	22	15	30	128
Age, mean (SD)	40.7 (16.2)	51.8 (18.3)	55.2 (17.4)	45.4 (17.3)	45.8 (17.7)
Female, n (%)	47 (55%)	19 (58%)	14 (54%)	23 (43%)	103 (52%)

Table 2. *Demographics: Patients' Descriptive Characteristics*

Characteristic	Value	CST n (%)	Controls n (%)	All n (%)	Characteristic	Value	CST n (%)	Control n (%)	All n (%)		
Gender	Female	66 (55%)	35 (44%)	101 (51%)	Employment	Employed	51 (43%)	28 (35%)	79 (40%)		
		50 (42%)					8 (7%)				
	Male	43 (54%)	93 (47%)	Unemployed		10 (8%)	12 (15%)	16 (10%)			
		3 (3%)				2 (3%)			6 (8%)		
Age	<30	37 (31%)	16 (20%)	53 (27%)	Marital Status	Retired	18 (15%)	18 (23%)	11 (18%)		
		19 (16%)					8 (7%)			3 (4%)	37 (26%)
		17 (14%)					24 (20%)				
		44 (37%)					49 (41%)				
	30-39	14 (18%)	11 (14%)	28 (14%)		Married	37 (31%)	14 (18%)	51 (26%)		
		11 (14%)					5 (4%)				
		82 (37%)					3 (3%)				
		38 (48%)					4 (3%)				
Race	White not Hispanic	2 (2%)	1 (1%)	3 (2%)	Stage at Diagnosis	Widowed	15 (13%)	9 (11%)	24 (12%)		
		10 (8%)					50 (42%)				
		7 (6%)					30 (25%)				
		2 (2%)					22 (18%)				
	Black	7 (9%)	7 (9%)	14 (7%)		Lives w/ Partner	15 (13%)	9 (11%)	24 (12%)		
		6 (8%)					50 (42%)				
		8 (10%)					30 (25%)				
		7 (9%)					22 (18%)				
Education	Asian Hispanic	2 (2%)	0 (0%)	2 (1%)	All	Missing	2 (2%)	1 (1%)	3 (2%)		
		7 (6%)					119				
		6 (8%)					80				
		8 (10%)					199				
	White/ Hispanic	7 (6%)	7 (9%)	14 (7%)		College	49 (41%)	28 (35%)	77 (39%)		
		2 (2%)					23 (19%)				
		22 (18%)					33 (28%)				
		14 (18%)					30 (38%)				
Other	2 (2%)	0 (0%)	2 (1%)	Postgrad	9 (11%)	16 (20%)	25 (12%)				
	0 (0%)				63 (32%)						
	2 (1%)				32 (16%)						
	36 (18%)				63 (32%)						
Missing	14 (18%)	30 (38%)	77 (39%)		All	119	80	199			
	14 (18%)					80					
	77 (39%)					199					
	30 (38%)										

Table 3. *Summary statistics for study measures*

Study Measures	<i>N</i>	<i>Mean</i>	<i>SD</i>	<i>Range</i>	<i>Skewness</i>	<i>SE</i>	<i>SK/SE</i>
<u>Number of Coping Strategies</u>							
Problem-focused	141	2.89	1.46	0-7	0.33	0.20	1.60
Emotion-focused	141	2.01	1.57	0-8	0.97	0.20	4.76
Total	141	4.90	1.97	1-11	0.49	0.20	2.42
Percent problem-focused coping	141	60.86	25.50	0-100	-0.18	0.20	-0.89
<u>Fear of Cancer Recurrence (FCR)</u>							
Baseline	124	1.38	1.00	0-4	0.94	0.22	4.32
6 months	116	1.02	0.88	0-4	0.91	0.23	4.02
12 months	112	0.99	0.91	0-4	1.24	0.23	5.44
<u>Square root transformations</u>							
Emotion-focused coping	141	1.40	0.55		-0.03	0.20	-0.17
FCR baseline	124	1.22	0.39		0.18	0.22	0.84
FCR 6 months	116	1.06	0.39		0.23	0.23	1.01
FCR 12 months	112	1.04	0.39		0.47	0.23	2.05

Note. Distributions were tested for normality by dividing skewness by its standard error (*SK/SE*), values over 3.29 indicating non-normality (West, Finch & Curran, 1995). A square root transformation corrected four positively skewed measures. A normalizing transformation (the square root) was applied prior to using these measures in the analyses to test the hypotheses.

Table 4. *Gender differences on coping strategies*

	Male (<i>n</i> = 62)		Female (<i>n</i> = 76)		<i>t</i>	<i>df</i>	<i>p</i>
	<i>Mean</i>	<i>SD</i>	<i>Mean</i>	<i>SD</i>			
Emotion-focused coping	1.26	0.51	1.51	0.56	-2.69	136	.008
Total coping	4.39	1.83	5.26	1.99	-2.67	136	.009

Table 5. *Total coping and problem-focused coping in those reporting modifiable versus fixed cancer causes*

	Fixed Causes (<i>n</i> = 42)		Modifiable Causes (<i>n</i> =50)		<i>t</i>	<i>df</i>	<i>p</i>
	<i>Mean</i>	<i>SD</i>	<i>Mean</i>	<i>SD</i>			
Total coping strategies	4.55	2.20	5.50	1.99	-2.16	84	0.034
Problem-focused coping strategies	2.83	1.68	3.24	1.44	-1.25	90	0.214

Table 6. *Coping strategies in those reporting stress as a cause of their cancer versus those who reported other causes*

	Stress Mentioned as a Cause				<i>t</i>	<i>df</i>	<i>p</i>
	Yes (<i>n</i> = 21)		No (<i>n</i> = 118)				
	<i>Mean</i>	<i>SD</i>	<i>Mean</i>	<i>SD</i>			
Problem-focused coping strategies	3.19	1.54	2.84	1.46	-1.01	137	0.314
Emotion-focused coping strategies	2.86	1.74	1.88	1.50	-2.60	137	0.010
Total coping strategies	6.05	2.22	4.72	1.87	-2.91	137	0.004

Note: for emotion-focused coping, square root was used in analysis; original means are shown

Table 7. *Slope analysis of baseline, six-month and 12-month FCR by high versus low Total Coping at six-months*

Source	Type III SS	df	MS	F	p
FCR across time	1.14	1	1.14	15.40	< .001
High/Low Total Coping	1.17	1	1.17	3.787	0.055
FCR * High/Low Total Coping	0.05	1	0.05	0.66	0.420
Error	6.49	88	0.07		

Note. High/Low coping was determined based on a median split. Where high coping = < 4

Table 8. *Pearson Correlations between Coping at six-months and Change in FCR*

Coping	Change in FCR					
	Baseline to 12 Months (n = 102)		Baseline to 6 Months (n = 105)		6 to 12 Months (n = 98)	
	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>	<i>r</i>	<i>p</i>
Problem-focused	-0.055	0.581	-0.026	0.793	-0.116	0.256
Emotion-focused	-0.061	0.544	-0.020	0.840	-0.012	0.907
Total	-0.105	0.292	-0.022	0.825	-0.130	0.202

Table 9. *Slope analysis of baseline, six-month and 12-month FCR by causal attribution of stress*

Source	Type III SS	df	MS	F	p
FCR across time	1.55	1	1.55	22.34	< .001
Stress caused cancer	0.16	1	0.16	0.50	0.480
FCR * stress caused cancer	0.46	1	0.46	6.68	0.011
Error	6.05	87	0.07		

Figure 1. Proposed model for Aim II: H1

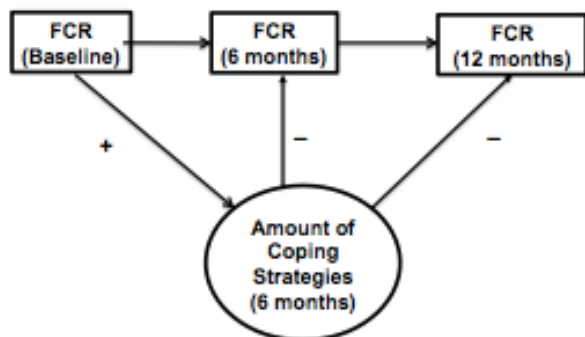
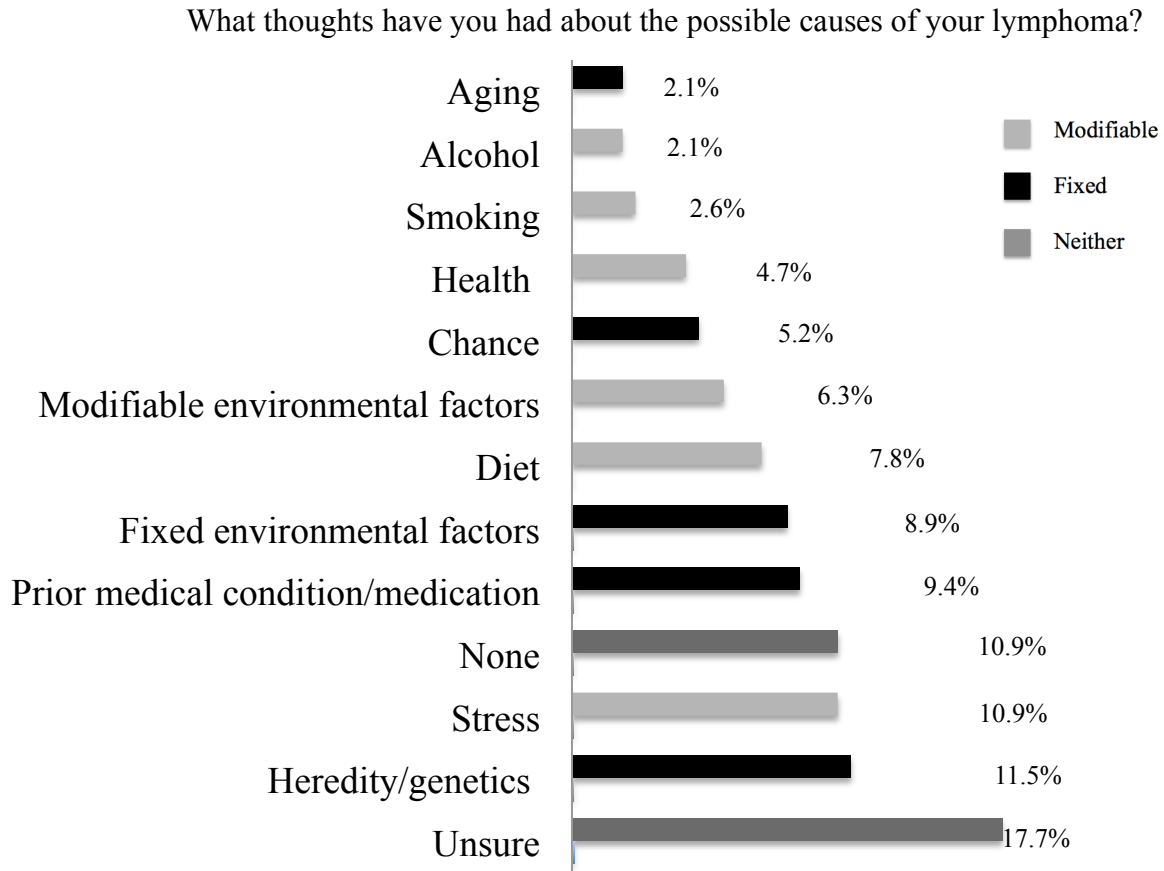


Figure 2. Categorical distribution of causal attributions.



Note. Percentages based on a total of 192 responses across 141 participants.

Figure 3. FCR across time by high versus low Total Coping at six-months

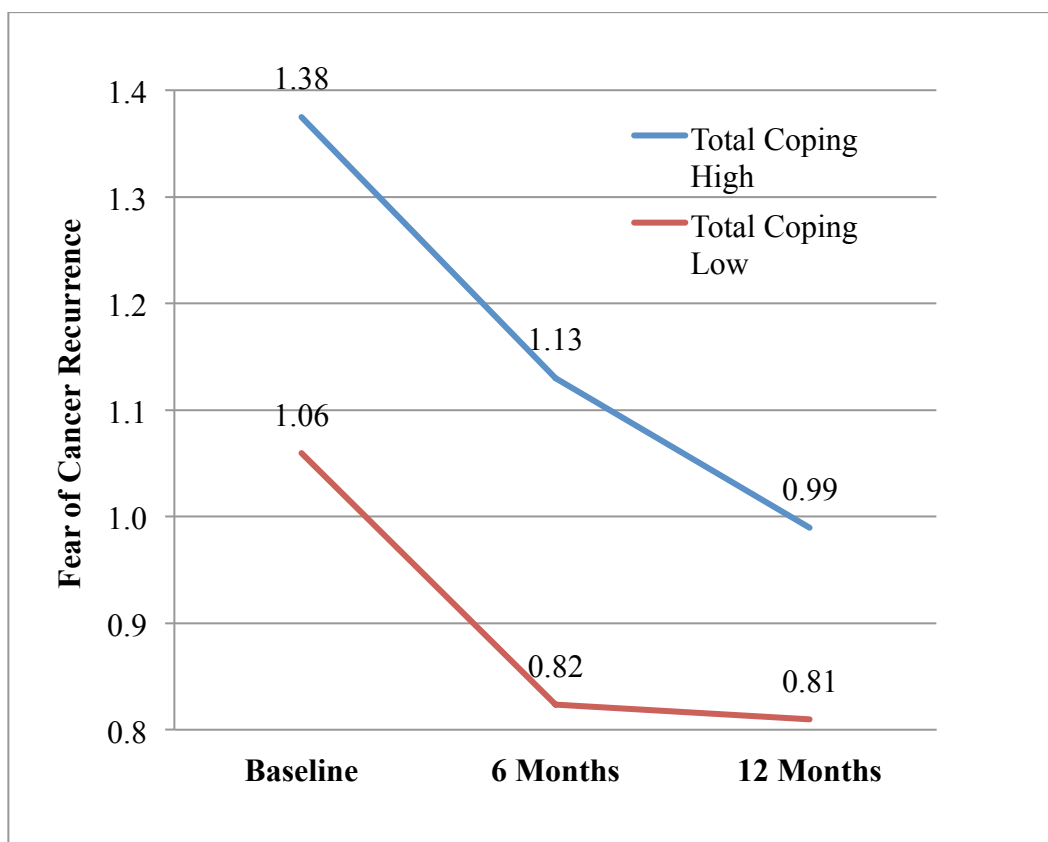
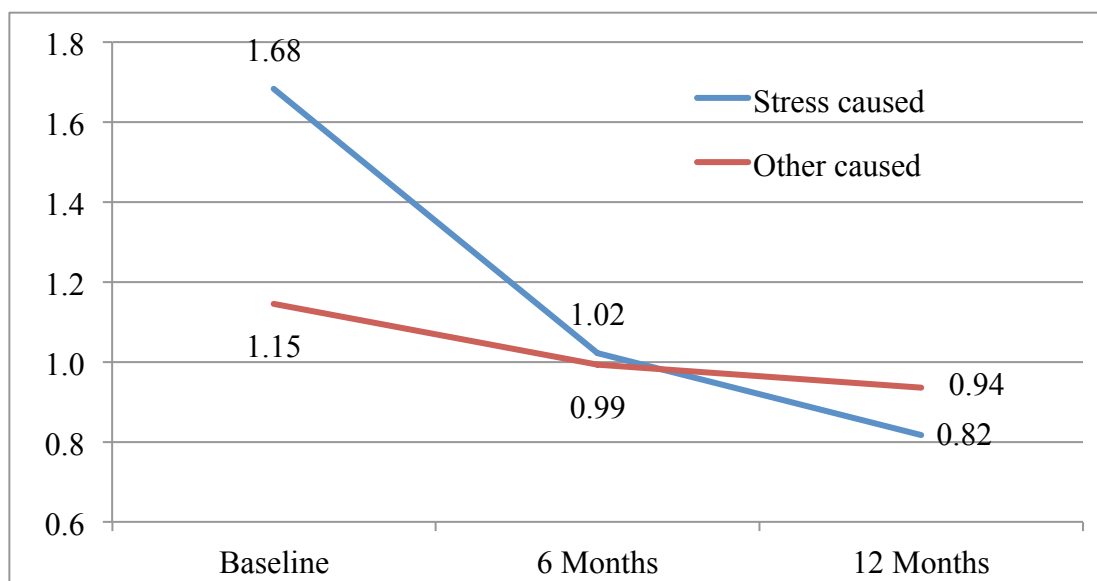


Figure 4. FCR across time by stress caused cancer versus others



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Appendix A. Six-month Qualitative interview: Qualitative Assessment for Lymphoma Survivorship Patients

1. Are you employed? No/Yes

If Yes:

a) What kind of work do you do?

b) So, are you [sitting/standing and walking] much of the time?

c) Do you have to concentrate on details for long periods of time? Yes ~~or~~ No

How many hours during a work day do you have to concentrate on details?

d) Overall, how many hours do you work each week?

2. What do you do at and/or around home?

Yes/No

If Yes – How many times a day/week?

Cooking; Cleaning; Laundry; Ironing; Taking kids to school; Shopping; Care provision to others; Other events

3. Do you feel you are back to your normal number and level of activities or very far from back? 1=Not at all, 4= 1/2 way Back, 7= all the way back

a) What are some of the barriers that you faced (and still face) in getting back to normal?

List

What did (do) you do about that?

How does it help and for how long?

4. Can you describe any specific things that you did to deal with these barriers; some things that seemed to work and some that didn't?

What worked?

What clued you in that it was working?

How long did it take before you noticed that?

What didn't?

How long/often did you try it?

Was it hard to work into your routine?

(include, as examples, graduated fitness programs, correction of anemia, diet, medications, etc.)

5. About how many weeks or months after you completed treatment did you begin to get back to your usual, pre-treatment level of activity?

What activities did you start first?

When did you get to the level of activities you are doing now?

6. Did your oncologist make some specific suggestions or suggest some general strategies that have helped you get your life back to normal? (Record Yes/No if patient gives response)

Yes / No

If patient says —"Yes", ask for and record specific examples:

Can you recall some specific suggestions that you tried?

1)

If YES

(& PROBE)

Did it fit into your daily pattern of activities? Did you have the energy to do it?

Did anyone help you get going?

How did it help?

2)

If YES

(& PROBE)

Did it fit into your daily pattern of activities? Did you have the energy to do it?

Did anyone help you get going?

How did it help?

Can you recall some specific suggestion that you did not try to do?

1)

Why not? (& PROBE)

Did it fit into your daily pattern?

Did you lack the energy to do it?

Did anyone dissuade you from doing it?

2)

Why not? (& PROBE)

Did it fit into your daily pattern?

Did you lack the energy to do it?

Did anyone dissuade you from doing it?

7. What sort of leisure activities do you enjoy doing now?

8. Are there some activities that you used to do that you've given up?

Yes / No

If yes: What are they?

Why did you stop?

Are you doing any new activities; something you did not do before treatment? Yes / No

What are they and what about them is enjoyable and/or helpful?

How did you fit doing it into your overall day?

Did you make an action plan?

9. Turning to worry about your lymphoma, how often do you WORRY THAT IT MIGHT [fear] COME BACK?

· Every day?

· Several days a week?

· At least once every week?

· Every other week?

· No more than once a month?

· Only near medical check-ups?

10. What thoughts have you had about the possible causes of your lymphoma?
11. Although treatment has eliminated any sign of your lymphoma, do you feel that the things that brought it on are still active in some way?
12. Did your oncologist tell you some things that helped you to worry less about the lymphoma coming back?
Yes / No
If Yes:
What did s/he say?
How was that helpful?
13. What are some of the things you did (do) on your own to keep your worry under control?
14. Do you feel that worry about recurrence has a negative effect on your quality of life?
15. Does worry about recurrence help to motivate you to take preventive measures?
What are some of these preventive measures?
16. Is there a family member or friend who has helped you deal with your worries about recurrence and survivorship?
Can you tell us what they did and/or said that was helpful?
17. Are there key symptoms you look for that might point to concern for recurrence?
If so, please list these:
18. How confident are you that you would recognize evidence of recurrence if this were to occur?
[Categorize as 1) very confident; 2) moderately confident; 3) mid-range; 4) mildly confident; 5) low level of confidence.]
19. In looking to your future health, what are the regular things you plan to do to optimize your wellness in the future? Please list:
For Each:
A) Have you made a plan to work that into your daily life?
For the most important one: Can you tell me a bit about the plan? (code whether it is specific or vague)
20. Are there cancer-screening tests that you plan to regularly undertake? If so, please list:
21. Give us a global rating between 1 and 10 as to how well you feel you understand the appropriate care plans that you should follow as a survivorship of lymphoma.
1= poor understanding and 10 = optimal understanding.

Appendix B. Cancer Worries Inventory (CWI; D'Errico et al., 1999)

Listed below are some issues that you may think about because of your illness. Thoughts about these issues may lead to worry or concern, but every issue may not apply to you.

HOW MUCH DID YOU WORRY ABOUT EACH OF THE FOLLOWING IN THE LAST SEVEN DAYS?

If an issue does not apply to you simply circle "0" for "None."

	None (0)	A little (1)	A fair amount (2)	Much (3)	Very much (4)
1. Nausea or vomiting					
2. Change in the way my food tastes					
3. If I will die from this illness					
4. My relationship with God					
5. Loss of appetite					
6. Having enough money to make ends meat					
7. Disrupting family holidays or special occasions					
8. Surgery					
9. The cancer will spread					
10. When I will die					
11. My religious beliefs					
12. Having enough money to live the way I'm used to					
13. Being an emotional burden to my spouse/partner					
14. Side effects of chemotherapy					
15. Treatment will not get all of the cancer					
16. The value and meaning of life					
17. Having to ask friends for help					
18. The family having to rearrange their lives					
19. Receiving radiation treatment					

20. Side effects of radiation treatment					
21. The cancer will come back					
22. Being a burden to my family					
23. How I have lived my life					
24. If there is life after death					

In the space below please write down the three most troubling thoughts you had about your illness during the past week, including today. If needed, please feel free to include thoughts which are not covered in the list above.

a. _____

b. _____

c. _____

Appendix C. Coding Scheme: Initial Coding of Transcribed Interviews from QI

Qualitative Interview (QI) (6 months- Qualitative Data)

- Turning to worry about your lymphoma, how often do you worry that it might [fear] come back? (9)
 - Worry of recurrence (1 = Every day; 2 = Several days a week?; 3 = At least once every week; 4 = Every other week; 5 = No more than once a month; 6 = Only near medical check-ups)
- What thoughts do you have about the possible causes of your lymphoma (10)
 - Summarize open-ended response
- What are some of the things you did (do) on your own to keep your worry under control? (13)
 - Summarize open-ended response
- Does worry about recurrence help to motivate you to take preventative measures? (15) What are some of these preventive measures? (15a)
 - Summarize open-ended response
- In looking to your future health, what are the regular things you plan to do to optimize your wellness in the future? Please list: (19)
 - List of things to optimize wellness (1 = general exercise; 2 = walking; 3 = running; 4 = swimming, 5 = meditation, 6 = general relaxation, 7 = others...write it out...)

Appendix D. Coding Scheme: Modifiable Causal Attributions

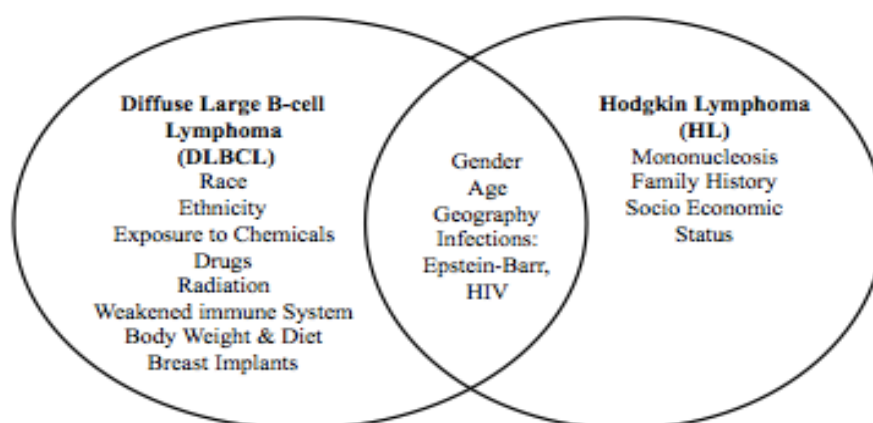
(Adapted from Ferucci et al., 2011)

Can the cause be modified? (Yes=1, No=0, Combined=2, Uncertain=3, None or no =9, Missing=800)

Broad Category	Individual Attribution Reasons	Modifiable
Lifestyle	Alcohol Tobacco Smoking Delay in healthcare Diet Use of hormones Lifestyle Reproductive history Harmful behavior	Yes
Biological	Aging Heredity/Genetics	No
Environmental	Modifiable Environmental Factors—experienced in the past but can be changed in the future (e.g. household chemicals, occupational hazards, toxins-including from body products, ink, food, water and plastic, sun exposure-work, second hand smoke)	Yes
	Fixed environmental factors—exposure occurred in the past and cannot change it in the future (e.g. Agent Orange, tattoo ink): none	No
Chance/Luck	Chance/Luck	No
Stress	Stress	Yes
Existential	God Predetermination Why not	No
Prior health condition	Infection Previous medical condition Trauma/Injury	No
Psychological	Character blame Deservedness Personality	No

Appendix E. Causes of Diffuse Large B-cell Lymphoma (DLBCL) and Hodgkin Lymphoma (HL)

While the specific etiology of HL and DLBCL is unknown, the American Cancer Society (2017) lists several risk factors for NHL, DLBCL, and HL including: gender, age, geography, and specific infections (e.g. Epstein-Barr virus infection, HIV). For NHL and DLBCL, other risk factors include: race, ethnicity, exposure to specific chemicals, drugs, radiation, having a weakened immune system or autoimmune disease, body weight and diet, and breast implants. For HL, those that differ from NHL and DLBCL include: mononucleosis, family history, and socioeconomic status (perhaps also linked to Epstein-Barr virus) (see *Figure 5*).



(American Cancer Society, 2017)

Figure 5. Causes of Diffuse Large B-cell Lymphoma (DLBCL) and Hodgkin Lymphoma (HL).

Appendix F. Coding Scheme: Coping Strategies

Emotion-Focused

- Attempts to manage emotions or feelings associated with the stressor.
- Targeting stress response.

Problem-Focused

- Acts on stressor directly to remove or reduce stressor.
- Targeting actual problem.
- Deals with the source of the stressor.
- Focuses on problem.

Sub-themes of Emotion & Problem-Focused Coping from the COPE Inventory (adapted from Litman, 2006)

Emotion-Focused	Problem-Focused
Reframing stressor in positive terms (i.e. positive reframing)	Active coping (e.g. taking actions to eliminate the problem)
Acceptance	Planning
Denial	Focusing on the problem solely (i.e. suppressing competing tasks)
Cognitive avoidance	Restraint Coping (i.e. finding the right moment to act)
Humor	Seeking advice (e.g. resources, experts--including attending medical appointments)
Behavioral distraction (e.g. to distract self from thinking about the problem, including substance use)	
Using faith/religion (e.g. prayer, church)	
Emotional support (e.g. seeking sympathy, venting/expressing, therapy, psychopharmacological medications, relaxation)	

Coping Type & Amount

How do you keep worry under control? (13)

- Problem-focused=1, emotion-focused=0, both=2, none=9, missing=800
- Count of coping strategies: 1) problem-focused; 2) emotion-focused

Does worry about recurrence help to motivate you to take preventative measures? What are those measures? (15a)

- Problem-focused=1, emotion-focused=0, both=2, none=9, missing=800
- Count of coping strategies: 1) problem-focused; 2) emotion-focused

In looking to your future health, what are the regular things you plan to do to optimize your wellness in the future? (19)

- Compare list of things to optimize health with Q2 (does worry about recurrence help to motivate you to take preventative measures (problem-focused). Code if not repetitive: Problem-focused=1, emotion-focused=0, both=2, none=9, same=10 missing=800
- Count of coping strategies: 1) problem-focused; 2) emotion-focused
- Three totals will be calculated inclusive of all strategies listed for 13, 15a, and 19. A total for problem-focused, emotion-focused and all strategies will be calculated.

Appendix G. Coding Scheme: Type of Causal Attribution

What type of cause was specified? (9=none, 800=missing)

Individual Attribution Reasons	Number
Alcohol	1
Smoking	2
Diet	3
Health (e.g. weight, lack of sleep, sedentary lifestyle)	4
Stress	5
Aging	6
Heredity/Genetics (e.g. “my relative has it”)	7
Modifiable Environmental Factors —experienced in the past but can be changed in the future (e.g. household chemicals, occupational hazards, toxins-including from body products, ink, food, water and plastic, sun exposure-work, second hand smoke)	8
Fixed environmental factors —exposure occurred in the past and cannot change it in the future (e.g. Agent Orange, tattoo ink): none	10
Chance (luck, random, etc.)	11
Previous medical condition (Epstein-Barr virus) or medication taken	12
Unsure (e.g. I don’t know)	14

Appendix H. Coding Scheme: Causal Related Coping

Individual Attribution Reasons	Related Coping Themes
Alcohol	Reduce alcohol
Smoking	Smoking Cessation
Diet (nutrition)	Modify Diet
Health (weight, sedentary, sleep, etc.)	Diet, Exercise (e.g. cardiovascular, walking), Improve Sleep, doctors visits
Stress	Relaxation strategies (see Appendix I)
Aging	None
Heredity/Genetics (e.g. “my relative has it”)	None
Modifiable Environmental factors: (e.g. household chemicals, occupational hazards, toxins-including from body products and food, previous sun exposure-work, second hand smoke)	Reduce exposure to toxins (e.g. second hand smoke, chemicals in plastic, more organic foods/products, sunscreen)
Fixed environmental factors (e.g. Agent Orange, tattoo ink): none	None
Chance (luck, random, etc.)	None
Previous medical condition (Epstein-Barr virus) or medication taken	None, but may see intake in vitamins and increase in healthy behaviors
Other: Pressure from seatbelt	Reduce exposure to specific problem

Appendix I. Causal Level Data Set Coding Rules

Coding Scheme for Causal attributions

Health

- Sample responses for **weight**: weight, overweight
- Sample responses for **health**: health, pretty unhealthy, not 100% on top of my health, not as healthy as I should be, unhealthy living habits, poor self-care, going to dr (e.g. finding new primary-care provider, going to scans, scheduling regular appointments).
- Sample responses for **lack of sleep**: late sleeping time, no sleep
- Sample responses for **sedentary**: sitting too long, not working out

Cause Related Coping Rules

Health

Coping for **health** category

- Weight: diet, exercise
- Health: diet, exercise, sleep, doctor visits
- Lack of Sleep: sleep
- Sedentary: exercise

Stress

Coping for **stress** category

- Relaxation strategies: refer to the variety of methods and manipulations used to reduce stress, muscle tension, and anxiety in the body (active coping).
- Responses from: **How do you keep worry under control?**

Stress Cause-Related Coping	Not a Cause-Related Coping Strategy
PROFESSIONAL HELP <ul style="list-style-type: none"> • Seeing stress management counselor, therapist, psychologist, music therapy • Taking anxiety or depression medication PHYSICAL ACTIONS <ul style="list-style-type: none"> • Breathing exercises • Marijuana • Relaxing • Cutting back on work/ not overdoing it • Yoga • Meditation, mindfulness- “living in the present” • Practicing cognitive strategies, cognitive reframing 	<ul style="list-style-type: none"> • Keeps busy w/ mind/ keeps distracted/ cognitive distraction • Behavioral distraction- keeps activated • Avoidance- not think about it • Developing or maintaining a positive attitude, staying positive. • Prayer, reading bible • Faith: “believing in the lord” “release control to God”

SOCIAL STRATEGIES <ul style="list-style-type: none">• Attend support group• Try to have more fun/ do more leisure activities/ hanging out with friends• Companionship with partner/ pets• Social support from friends, spending time with family, church• Surround myself by positive people/environments	
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