An Exploratory Path Model of the Relationships between Positive and Negative Adaptation to Cancer on Quality of Life among non-Hodgkin Lymphoma Survivors

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Abstract

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Purpose—Adaptation is an ongoing, cognitive process with continuous appraisal of the cancer experience by the survivor. This exploratory study tested a path model examining the personal (demographic, disease, and psychosocial) characteristics associated with quality of life (QOL) and whether or not adaptation to living with cancer may mediate these effects.

Methods—This study employed path analysis to estimate adaptation to cancer. A cross sectional sample of NHL survivors (N=750) was used to test the model. Eligible participants were 18 years, at least two years post-diagnosis, and living with or without active disease.

Results—68% of the variance was accounted for in QOL. The strongest effect (−0.596) was direct by negative adaptation, approximately three times that of positive adaptation (0.193). The strongest demographic total effects on QOL were age and social support; <65 years of age had better QOL and better adaptation compared to those 65. Of the disease characteristics, comorbidity score had the strongest direct effect on QOL; each additional comorbidity was associated with a 0.309 standard deviation decline on QOL. There were no fully mediated effects through positive adaptation alone.

Our exploratory findings support the coexistence of positive and negative adaptations perception as mediators of personal characteristics of the cancer experience. Negative adaptation can affect QOL in a positive way. Cancer survivorship is simultaneously shaped by both positive and negative adaptation with future research and implications for practice aimed at improving QOL.

Introduction

An increase in the number of cancer survivors has generated interest in exploring the long-term impact of cancer on health related quality of life (QOL) and on demographic and disease factors that are associated with adaptation to living with this chronic disease. There is accumulating evidence indicating that non-Hodgkin Lymphoma (NHL) survivors' QOL varies; they report both positive and negative outcomes from their diagnoses and treatments (Arden-Close, Pacey, & Eiser, 2010; Bellizzi, Miller, Arora, & Rowland, 2007; Mols et al., 2007; Reeve et al., 2009). NHL accounts for about 4% of all cancers in the United States with an expected new incidence of 71,850, and 19,790 expected deaths for 2015 (American Cancer Society, 2015). As patients survive longer with NHL, factors that impact their QOL including unfavorable physical and psychological long term effects, secondary malignancies, and illness perceptions that can negatively effect overall QOL (Oerlemans et al, 2012; Husson et al, 2013; Jensen et al, 2013). To extend our understanding of QOL in survivorship, we must consider physical, social and family, emotional, and functional well-being as separate domains and together as an overall QOL domain (Cella et al., 1993; Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995; Ferrell, Dow, & Grant, 1995).

Cancer-related QOL does not typically capture positive life changes, personal growth or negative changes; hence, the need for an instrument that captures each construct separately (Zebrack, Ganz, Bernaards, Petersen, &Abraham, 2006). For example, positive adaptation includes, but is not limited to being altruistic and empathic, being aware of health needs, understanding the meaning of cancer, and a positive self-evaluation and for negative adaptation includes, but is not limited to, appearance and body concerns related to treatment,

life interferences due to the disease and/or treatment, and worrying about health and life events (Zebrack, Ganz, Bernaards, Petersen, &Abraham, 2006).

There is a large body of literature documenting that individuals with cancer report perceived benefits and personal growth – and that these perceived positive adaptations co-exist with distress and negative adaptation (Sears, Stanton & Danoff-Burg, 2003; Smith, Williams, Zimmer & Zimmerman, 2011; Smith et al, 2011). There are various models in which stress and adaptation theories emphasize internal and external resources that promote adaptation (Lazarus & Folkman, 1984; Taylor & Aspinwall, 1996). Research has focused primarily on negative adaptation, but we suggest that exploring positive adaptation is also important as we understand the overlap and distinctness of positive and negative adaptation (Sears, Stanton & Danoff-Burg, 2003; Smith, Williams, Zimmer & Zimmerman, 2011; Smith, Williams, Zimmer et al, 2011). We suggest exploring these cancer-related QOL constructs separately. In a parent study of NHL survivors, post-traumatic stress disorder (PTSD) symptomatology mediated the relationship between specific stressors (e.g., comorbidities) and QOL (Smith, Williams, Zimmer et al 2011). In the follow-up study five years later, authors found that over one-third (37%) of survivors had persistent or worsened post traumatic symptoms and 42% of these NHL survivors had persistently low or worsening age-adjusted QOL since the initial survey (Smith, Zimmerman, Williams, Benecha, et al, 2011). Additional studies support that long-term survivors experience post traumatic effects that can manifest through distressing symptoms (i.e., anxiety and depression) (Sears, Stanton & Danoff-Burg, 2003; Leak et al, 2013).

A cancer diagnosis often represents a turning point for many individuals; one that rarely has a completely negative or completely positive impact on QOL. Leak et al (2013) explored the relationship of demographic and disease characteristics on QOL and examined the moderating effect of age among NHL survivors. Leak et al (2013) found that younger NHL survivors (<65 years of age) with <$30,000 income had poorer QOL compared to older NHL survivors (>65). Additionally, females had higher overall QOL than males. Time since diagnosis and the treatment period (e.g. active or surveillance) may also be contributing factors for either improved or decreased QOL in younger survivors and female survivors. Longitudinal studies would provide a more definitive answer as to whether demographic and disease characteristics differentially impact QOL changes with increasing age.

Understanding positive and negative adaptation that cancer and its treatments may have on the long-term health and overall QOL of NHL survivors is an important aspect of survivorship care; and, by doing this, it can inform development of new psychosocial interventions. It is hypothesized that positive adaptation has a positive association with cancer-focused QOL and negative adaptation has a negative association with cancer-focused QOL. Thus, the primary purpose of this exploratory study was to investigate whether or not positive and negative adaptation to living with cancer may mediate the effects of survivors' personal characteristics on cancer-focused QOL. This analysis continues the work of the parent and follow-up studies that found while most survivors reported good QOL, approximately 1/3 continue to experience symptomatology and poor QOL related to their diagnosis and treatment for lymphoma.

Conceptual Framework

The cancer survivor adaptation (CSA) model of QOL among NHL survivors used in was this study was adapted from Naus, Ishler, Parrott, and Kovacs' model (2009). It has three components: personal characteristics, adaptation, and outcome, as shown in Figure 1. The CSA model proposes that *personal characteristics*, which include demographic, disease, and psychosocial factors, can have direct positive or negative associations with QOL, the *outcome* studied here. In addition, they can have indirect effects on QOL through positive or negative adaptation to cancer. We present three explicit hypotheses regarding how positive and negative adaptation relates to QOL. However, due to the many personal characteristics in the model, individual hypotheses are not listed for each one.

Adaptation, the fundamental component of this model, is an ongoing, cognitive process involving continuous appraisal of the survivor's situation (Naus, Ishler, Parrott, & Kovacs, 2009). It can take two forms, either positive or negative. Positive adaptation has favorable psychosocial implications for QOL, such as better coping skills and encompasses altruism and empathy, health awareness, understanding the meaning of cancer, and positive self-evaluation. Negative adaptation focuses on appearance concerns, body change concerns, life interferences, and worry which have unfavorable physical or psychological QOL outcomes ((Zebrack, Ganz, Bernaards, Petersen, &Abraham, 2006). The hypotheses for this study were:

> Hypothesis 1: Positive adaptation has a positive association with cancer-focused QOL.

> Hypothesis 2: Negative adaptation has a negative association with cancer-focused QOL.

> Hypothesis 3: Positive and negative adaptation are mediators between personal characteristics and QOL.

Method

Study Design

The analysis was performed on data from a cross-sectional study of NHL survivors previously described (Smith, Zimmerman, Williams, Preisser, & Clipp, 2008). The primary aim of the parent study was to estimate the prevalence of post-traumatic stress disorder (PTSD) symptoms in survivors of adult NHL who were at least two years post-diagnosis and to identify risk factors associated with PTSD symptoms for the study population (Smith, Zimmerman, Williams, Preisser, & Clipp, 2008).

Participants and Procedures

The data were accrued through mailed surveys per the Dillman method; additional details are reported elsewhere (Smith, Zimmerman, Williams, Preisser, & Clipp, 2008). Participants were NHL survivors treated at one of two comprehensive cancer centers in North Carolina: Duke University and the University of North Carolina at Chapel Hill's Lineberger Comprehensive Cancer Centers. *Survivors* were defined as individuals after diagnosis, whether or not they had active disease (National Coalition for Cancer Survivorship, n.d.). Hence, eligibility criteria for the parent study included being 18 years of age or older, at

least two years post diagnosis, and either currently receiving treatment, in remission, or cured (Smith, Zimmerman, Williams, Preisser, & Clipp, 2008). Approval for all study procedures were obtained from the Institutional Review Boards at the University of North Carolina and Duke University.

Measures

Quality of Life—The 27-item Functional Assessment of Cancer Therapy-General, version 4 (FACT-G) (Cella et al, 1993) was used to measure general cancer–related QOL outcomes in physical (PWB), social and familial (SFW), emotional (EWB), and functional well-being (FWB) realms. The total FACT-G was used as the QOL outcome. Satisfactory reliability and validity for the FACT-G has been reported in initial psychometric studies (Cella et al, 1993; Leak et al, 2013). The reliability of the FACT-G subscales and total score ranged from 0.77 to 0.93 in the parent study (Smith, Zimmerman, Williams, Preisser, & Clipp, 2008). In the current study, four subscales served as indicators of the observed variable, QOL, after a confirmatory factor analysis and a calculation of Cronbach's alpha to establish reliability of the QOL scale. which was part of the overall explanatory model of QOL.

Adaptation—The Impact of Cancer (IOC) Scale, version 2, is a 37-item scale used to measure perceptions of positive and negative aspects of one's life as they relate to cancer (Zebrack, Ganz, Bernaards, Petersen, & Abraham, 2006). Positive and negative adaptations are measured with the IOC scale. For this study, the IOC was used to measure adaptation to living with cancer. The four positive subscales were altruism and empathy, health awareness, understanding of the meaning of cancer, and positive self-evaluation. The negative subscales were appearance concerns, body change concerns, life interferences, and worry. Higher scores overall on the positive subscales indicate more positive adaptation, and higher scores on the negative subscale indicate more negative adaptation. Positive and negative adaptations were measured as observed variables with their corresponding subscales as indicators in two confirmatory factor models within the CSA Model. The factor loadings and Cronbach's alpha were calculated to establish reliability of the positive and negative scales The reliability of the Positive and Negative Impact summary scores were α= 0.90 and 0.91 in the parent study (Smith, Zimmerman, Williams, Preisser, & Clipp, 2008).

Personal Characteristics—The personal characteristics in the CSA Model included demographic variables which were self-reported. The demographic variables were age at time of study, gender, race, ethnicity, education level, marital status, and income.

Disease Factors—The disease variables included NHL histology, stage at diagnosis, remission status, currently receiving treatment, cancer treatment(s) undergone (i.e., surgery, radiation therapy, chemotherapy, biologic therapy, bone marrow transplantation [BMT] and/or stem cell transplantation [SCT]), years since diagnosis, and comorbidity score. These variables were collected via self-report and through the Tumor registries.

Psychosocial Variables—Social support is characterized as a psychosocial variable and was collected by self-report using the 20-item Medical Outcomes Study-Social Support Survey (MOS-SS) (Sherbourne & Stewart, 1991). This survey measured perceived

availability of social support and scores ranged from 20–100 (Sherbourne & Stewart, 1991). The reliability of this scale was 0.97 in the parent study (Smith, Zimmerman, Williams, Preisser, & Clipp, 2008). The MOS-SS has been widely used in a variety of illness populations, including long term breast cancer survivors (Ganz et al, 2003). Employment status is viewed as a psychosocial variable because it can impact the outcome.

The self-administered comorbidity questionnaire, a 12 item self-report version of the Charlson Index was used to assess past and current health conditions (Sangha, Stucki, Liang, Fossel, & Katz, 2003). Selected questions related to health care use and secondary cancer status were adapted from the Childhood Cancer Survivors Study survey (St. Jude Children's Research Hospital, 2013). The conditions listed were heart disease, high blood pressure, lung disease, diabetes, ulcer or stomach disease, kidney disease, liver disease, anemia or other blood disease, cancer other than lymphoma or non-melanoma skin cancer, depression, osteoarthritis or degenerative arthritis, back pain, and rheumatoid arthritis. There were also two open-ended spaces for conditions that could be specified by the participant. The comorbidity score consisted of the sum of the answers to three questions for each of the thirteen conditions: 1) whether the participant had ever been seen for the listed condition, 2) whether they were currently receiving treatment for the condition, and 3) whether their function was limited by the identified condition. A binary answer (*yes-1* or *no-0*) was supplied for each question. The total comorbidity score ranged from 0 to 30 with higher scores indicating a greater comorbidity burden and lower scores indicating a lower burden. All demographic, disease, and psychosocial characteristics were measured as observed variables in the path model.

Data Analyses

Descriptive statistics were computed for this secondary analysis using SPSS, version 14 statistical software. Confirmatory factor analyses were performed on multi-indicator indices to test how well they perform as coherent measures. Path analyses were conducted to test the CSA model of personal (demographic), disease, and psychosocial characteristics, positive and negative adaptation, and QOL. All explanatory analyses were estimated using MPlus version 7.11. Path modeling was the strategy because positive and negative adaptation, as well as QOL, were measured as observed variables in a causal structure. As stated above, we wanted to explore whether the effects of personal characteristics on QOL are mediated by positive and negative adaptation. All observed variables used in the path analyses had < 5% missing data. We initially included disease stage at diagnosis in the model, but it was not statistically significant in any part of the model. Hence, to reclaim 155 (12.9%) missing cases for the analysis, we dropped it from further modeling. In conducting path modeling, it is important to include variables and paths that are both supported mathematically and reflect theoretically meaningful relationships. A number of fit indices were used to assess model fit as suggested by the guidelines for path modeling Bollen, 1989). We used the χ^2 test of model fit, the comparative fit index (CFI), the Tucker-Lewis index (TLI), and the root mean square error of approximation (RMSEA) as measures to evaluate the fit of the path model. An adequate fit is indicated by a non-significant χ^2 statistic, a value of 0.90 or greater for the CFI and TLI, and a value of 0.05 or smaller for the RMSEA (Brown &

Cudeck, 1993). We report findings for the path model with non-significant paths trimmed. Standardized coefficients are reported to enable their comparison.

Results

Sample

There were 1,195 eligible NHL survivors, and 886 responded to the surveys, with a 74% response rate (Smith, Zimmerman, Williams, Preisser, & Clipp, 2008). We report descriptive statistics for the 750 survivors who were analyzed in the final trimmed model. Though some variables had missing data, MPlus uses pairwise present analysis for all variables with missing data, except in the case of exogenous variables where listwise deletion is used. The sample demographics are given in Table 1. The average age at the time of study enrollment was 62.4 (*SD* 13.4, range 26–92). The participants were evenly split between genders. Fourteen percent were of racial backgrounds other than Caucasian. The majority (76.4%) were married or living with a partner. Over half of the participants were either retired or unemployed (57.6%) and 27.8% earned less than $30,000 annually. The mean years since diagnosis were 10.3 (*SD* 7.0; range 2–44). The mean total comorbidity score was 5.6 (*SD* 4.9; range 0–30) which indicates a moderate comorbidity burden.

Survivors were about evenly divided in their disease histology with 49.1% indolent and 45.1% aggressive. Of these survivors, 27.6% had Stage I cancer and 24.1% had Stage IV cancer. A large proportion self-reported being in remission (78.7%) and an even larger percentage were no longer in treatment (86.2%). A majority of the sample reported having had chemotherapy (79.6%) and radiation (48.3%) as part of their treatment. Other reported treatments included biologic therapy (30.1%), surgery (30.8%), and Bone Marrow Transplantation/Stem Cell Transplantation (BMT/SCT) (15.8%).

Confirmatory Factor Analysis (CFA)

Measurement Models—We used CFA to assess how well QOL, PIS, and NIS measures held together. Measurement models for the three observed variables, QOL, positive impact score (PIS), and negative impact score (NIS) were estimated. The results from the trimmed model are shown in Table 2. Higher loadings, lower measurement error and higher R^2 values indicate a stronger relationship between the observed variables and their indicators (Baron & Kenny, 1986; Kline, 2005).

All factor loadings and R^2 values in Table 2 were statistically significant. The factor loadings of the indicators of QOL were strong, ranging from 0.613 to 0.839. The R^2 ranged from 0.376 to 0.704 and Cronbach's alpha for the scale was 0.812. This suggests a good fit. The PIS factor loadings ranged from 0.524 to 0.783. The R^2s ranged from 0.307 to 0.668 and Cronbach's alphas for the scale was 0.795. This suggests a good fit. The NIS factor loadings ranged from .554 to .817. The R^2s ranged from 0.307 to 0.668 and Cronbach's alphas for the scale was 0.794. This suggests a good fit.

Path Model Fit—The full hypothesized model, as shown in Figure 1, included observed variables. When estimated, the fit of the model to the data was: χ^2 =52.526 (*df* =15), p<0.001, CFI =0.969, TLI = 0.919, RMSEA = 0.058, N=750. The χ^2, CFI, TLI, and

RMSEA combined fit statistics suggest a good model fit. To improve model fit, we looked at adaptation separately. We did not examine potential areas of invariance in measurement, however we did compare the path model results by recent and long term survivors and found no change in the results. To ease the computation of indirect effects in the model, only significant paths ($p < .05$) were included in the trimmed version of the model (Baron & Kenny, 1986; Kline, 2005). Detailed model results are presented here, with the measurement models discussed first and the path part of the model discussed second.

Path Model: Mediation Results—The trimmed mediation model allowed for the examination of potential intervening variables (PIS and NIS) that linked survivors' personal characteristics to the outcome variable, QOL. A direct effect, unmediated, is a path from one of the model variables to another. All direct effects are shown in Figure 2. Table 3 lists the decomposition of effects in the model direct, mediated or indirect effects, total effects, and mediation form of all variables in the trimmed model on QOL.

Direct effects—There were direct effects from five personal characteristics on QOL: employment, income, age at time of study, social support, and total comorbidity score. As hypothesized, these mediating effects were possible because positive adaptation had a direct positive effect (direct effect=0.193) and negative adaptation had a large direct negative effect (direct effect=−0.596) on QOL. Higher PIS was associated with younger (<65) age and more social support. To test empirical separability, we compared a measurement model with indicators of both PIS and QOL observed variables loading on one single factor. This model did not fit as well as a model with the 2 observed variables separated. The model with PIS and QOL was the better fitting model. Also, there was a strong relationship between negative adaptation and QOL but, after testing, we found that they were distinct constructs.

Mediated/Indirect effects: Partial Mediation and Full Mediation—The effects of employment and income on QOL were unmediated. Those with a college degree biologic therapy, and have received a BMT/SCT had greater negative adaptation compared to those who were female, being of Non-Caucasian race, currently receiving treatment and have received chemotherapy had both positive and negative adaptation.

No Mediation—As shown in Figure 2 and Table 3, being employed increased survivors' QOL slightly (direct effect=0.083). However, having an income less than $30,000 reduced QOL (direct effect=−.091).

No Effects on QOL—Variables that were not statistically significant in the trimmed model were ethnicity, marital status, age at diagnosis, ethnicity, NHL histology, remission status, certain cancer treatments (e.g., surgery, radiation therapy, biologic therapies, and other therapies), and disease stage at diagnosis. The full model is presented in Figure 1.

Partial Mediation—The total effect of a personal characteristic on QOL is the sum of the direct effect on QOL and the indirect effect(s). The total effect of the comorbidity score is negative (total effect=−0.309, the sum of a negative direct and indirect effect), so a survivor with a higher comorbidity score has a lower QOL.

Older survivors had higher QOL than their younger counterparts (total effect=0.175). This effect is partially mediated by a small negative effect through PIS (indirect effect=−0.022) and a small positive effect through NIS (indirect effect=0.081). Similarly, the strong positive effect of social support on QOL was partially mediated by a positive indirect effect of social support on QOL through both PIS and NIS (total effect=0.429).

Full Mediation—No fully mediated effects were identified through PIS alone. College graduates had higher QOL (total effect=0.057). This effect is entirely due to college graduates having less NIS and NIS directly reducing QOL. Having received biologic treatment or BMT/SCT for cancer reduces survivors' QOL.

The remaining personal characteristics have effects that are fully mediated by PIS and NIS. Women have higher QOL overall than men (total effect=0.061). The mediated effect of sex through PIS is weak, but positive (indirect effect=0.023) and through NIS is twice as large and positive (indirect effect=0.038).

Those currently receiving treatment had lower QOL with a total effect of −0.087, the sum of two negative, indirect effects. Finally, having received chemotherapy somewhat lowered QOL with a total effect of −0.036, the sum of a weakly positive indirect effect through PIS and a more strongly negative indirect effect through NIS.

Discussion

At the heart of this analysis are the strong relationships between negative and positive adaptation and QOL. Our findings support our hypotheses that positive adaptation has a positive association with cancer-focused QOL and negative adaptation has a negative association with cancer-focused QOL. Negative adaptation was associated with decreased QOL; whereas positive adaptation yielded better QOL, and the results describe how adaptation serves to mediate the relationship between demographic and disease characteristics and QOL. Positive and negative adaptation may be a pathway to QOL and should be further investigated. There were direct effects of employment, age, social support and total comorbidity score on QOL. Many of these effects were partially mediated, and the effects of other personal characteristics were fully mediated, by positive and negative adaptation. These findings are consistent with Smith et al (2011) study that found posttraumatic stress disorder (PTSD) had a stronger association with QOL as compared to post traumatic growth.

Of the personal (demographic) and psychosocial characteristics impacting QOL, only income and employment were unmediated. Non-Caucasian survivors reported higher negative and positive adaptation and a corresponding indirect effect on QOL through both mediators. The higher negative adaptation was associated with a QOL decrease and the higher positive adaptation with a QOL increase, yielding no overall effect of race on QOL.

Secondly, the strongest demographic total effects were age (0.175) and social support (0.429). Older adults with NHL had better QOL than younger survivors. This may be explained in that older adults have experienced other significant life events or stressors and have learned how to manage these life changes, unlike younger survivors, which has found

that they have fewer coping skills to manage their illness and the thought of an early death may contribute to greater distress (Stanton, 2006; Thewes, Butow, Girgis, & Pendlebury, 2004). Older adults were less likely to report negative adaptation compared to younger survivors, and this is similar to previous findings (Bower et al, 2005; Blank & Bellizzi, 2006). With additional social support (ie. formal and informal), survivors may have had more coping resources which provided a positive effect on QOL.

Thirdly, comorbidity scores had the strongest effect (−0.309) on QOL of all the disease characteristics. With each additional comorbid condition survivors experienced, QOL declined by 0.309 standard deviations. The Institute of Medicine (IOM) report, *Ensuring Quality Cancer Care (2006)*, states that in caring for survivors with cancer, adequate measures should be taken to also address comorbidities (Hewitt & Simone, 1999; Ko & Chaudhry, 2002). Survivors with comorbidities present a challenge for cancer management as the number and type of comorbidity increases, QOL is poorer. Studies have reported that age and comorbidities are positively correlated; increasing age is associated with poorer physical health but higher psychological health (Hewitt & Simone, 1999).

The exploratory nature of the CSA path model (Figure 1) tested relationships between personal characteristics, positive and negative mediators, and QOL. Our findings supported that positive and negative adaptation helped to explain the relationships between personal characteristics and QOL. The QOL model we tested (Figure 2) explained a large amount of the variance (68%) with many key personal characteristics important in NHL survivorship. Our findings are consistent with the literature as it relates to positive and negative adaptation and the effects of personal, demographic and psychosocial characteristics on QOL (Smith, Williams, Zimmer, Zimmerman, 2011; Yancik, Ganz, Varricchio, & Conley, 2001). Thus, the model incorporated direct, indirect, and total effects of personal characteristics providing a basis for hypothesizing specific relationships among these variables. There are stronger associations of QOL with PWB and FWB as indicated by factor loadings >.80 and R^2 >.64. These 2 dimensions of overall QOL have shown to either improve or decrease QOL in NHL cancer studies (Oerlemans et al, 2012; Leak, Mayer, & Smith, 2011).

The personal characteristics of ethnicity, marital status, <$30,000 for income, employment status, and age at diagnosis had no direct effects on QOL. Additionally, certain cancer treatments such as surgery, radiation and biologic therapies did not have direct effects on QOL. Conceptually, these cancer treatments alone do not capture the complexity of QOL (Leak, Mayer, & Smith, 2011). These findings are consistent with prior studies that reported significant (e.g., social support) and non-significant (e.g., income) associations of certain sociodemographic variables (eg. income) with QOL outcomes for breast and lymphoma cancers Northhouse et al, 2002; Kornblith et al, 2003; Geffen, Blaustein, Amir, & Cohen, 2003).

The observed variables (QOL, PIS, and NIS) and the direct assessments for PIS (altruism and empathy, health awareness, meaning of cancer, and positive self-evaluation) and NIS (appearance concerns, body concerns, life interferences, and worry) were well measured by their indicators. Although overall, the path model did fit well, our goal was not to fully capture all determinants of QOL, but to explore the mediation of personal characteristics on

QOL through positive and negative adaptation. The exploratory path model presented does not build a QOL model, but we found several important relationships while doing so that provides support that adaptation is simultaneously shaped by both positive and negative perceptions. Positive adaptation did not serve as a strong mediator compared to negative adaptation; however it provides a foundation for additional personal characteristics to be explored for potential contribution to the model. Bellizzi et al (2007) found that 78% of NHL survivors reported at least one positive and one negative change in their lives related to their cancer experience.

This study has implications for both practice and research. Equipping this population with information and resources early in their illness trajectory will emphasize not only the positive changes adaptation may bring but give them ways to identify and overcome the negative effects of the cancer experience. Hopefully, with early intervention, cognitive appraisal processes will adapt faster as stressors and psychological growth occurs, reflecting integration into a new way of life (Conway, 2005; Conway, Meares, & Standart, 2004; Conway & Pleydell-Pearce, 2000). QOL changes occur differently in each QOL domain, which may aid newly diagnosed survivors in recognizing that positive and negative coping behaviors are expected to occur. It is hoped that this understanding may help them reintegrate into their social environments. Physical and functional well-being had stronger associations with overall QOL warranting continued interventional work to improve QOL in these specific domains. These exploratory findings support and extend the current NHL literature and the CSA model.

Limitations

Although the study provided important insight into the QOL of NHL survivors and their adaptation to cancer, there are some limitations to consider. This study was a cross-sectional, secondary analysis and thus was limited in determining causal processes and relationships among factors. This analysis provided suggestions for causal models, but longitudinal research is needed to delineate the processes that link personal, disease, psychosocial characteristics, adaptation to cancer, and QOL. Longitudinal research will also allow assessment of varying adaptation patterns over time and of how to intervene at the most critical points of the survivorship trajectory.

The results may not be generalizable to other cancers or to other geographical locations. The model could be re-tested by employing other QOL measures, such as the European Organization for Research into Treatment of Cancer (EORTC) and/or Quality of Life-Cancer Survivors (QOL-CS) scales. Additional variables of interest that could be included in the QOL model are psychosocial variables such as anxiety, depression, and distress.

Strengths

A strength of this study is the development of a conceptual model that incorporates demographic and disease characteristics, adaptation, and QOL factors. The conceptual CSA model identified theoretically meaningful relationships among the factors, and its final state incorporating the study's results can be seen in Figure 2. It is clinically relevant and encourages healthcare providers to ask NHL survivors about adjusting to living with cancer

and the coping process to provide resources to them throughout the survivorship period. Additional strengths of the study include an excellent response rate and a large sample of a cancer-specific population in a diverse state. Also, a substantial proportion of the variance in QOL was accounted for (i.e., the squared multiple correlations between the observed variables). This study also supported the idea that negative adaptation to cancer is associated with decreased QOL and potentially negative health outcomes (Bellizzi, Miller, Arora, & Rowland, 2007). In a longitudinal study of NHL survivors, Smith, Zimmerman, Williams, Benecha et al (2011) found that more than one-third of survivors experienced persisting or worsening PTSD which is associated with negative adaptation during the survivorship period.

In summary, both positive and negative adaptation were important mediators of the exploratory relationships between demographic, disease, and psychosocial characteristics and QOL. These data illustrate the usefulness of the IOC as a general cancer-specific measure of positive and negative adaptation and shows evidence of the need for intervention work with this population. A negative perception of cancer is a stronger mediator than positive adaptation on QOL outcomes. Interventions tailored to assist survivors' in cognitively reframing their experiences may be useful and may result in decreased adverse health outcomes and increased QOL.

The CSA model was tested using a path model. Significant theorized relationships were supported by the data. Positive and negative adaptation mediated some effects of demographic and disease characteristics on QOL. Further research is needed to expand our knowledge of positive and negative adaptation to cancer can have overlapping effects on survivors' and also on the caregivers and families of survivors. Interventions are needed to target support to NHL survivors to improve their abilities to reduce the negative effects of cancer and to support them in seeing the positive changes and benefits of living with the disease.

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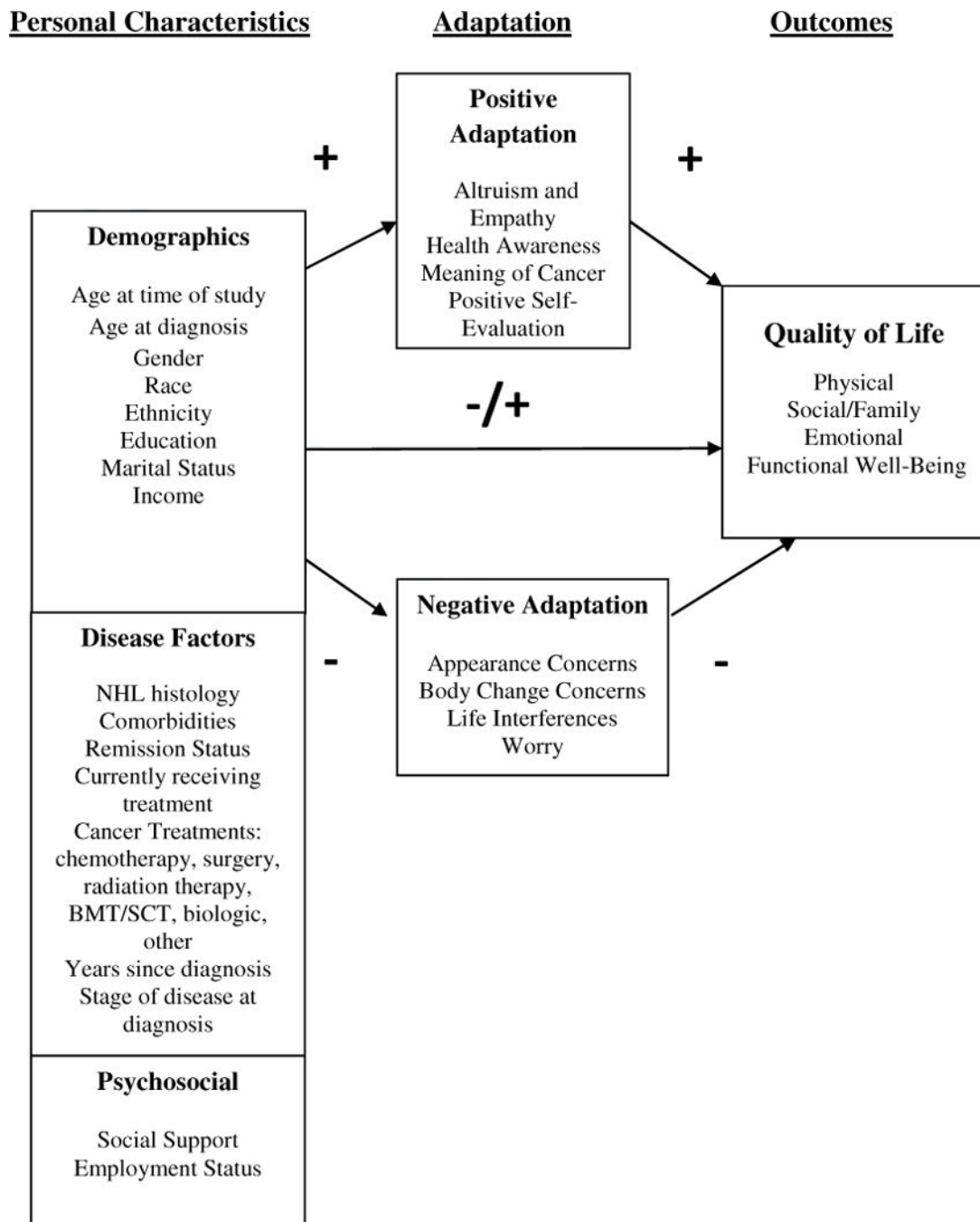
Figure 1. The Cancer Survivor Adaptation Model
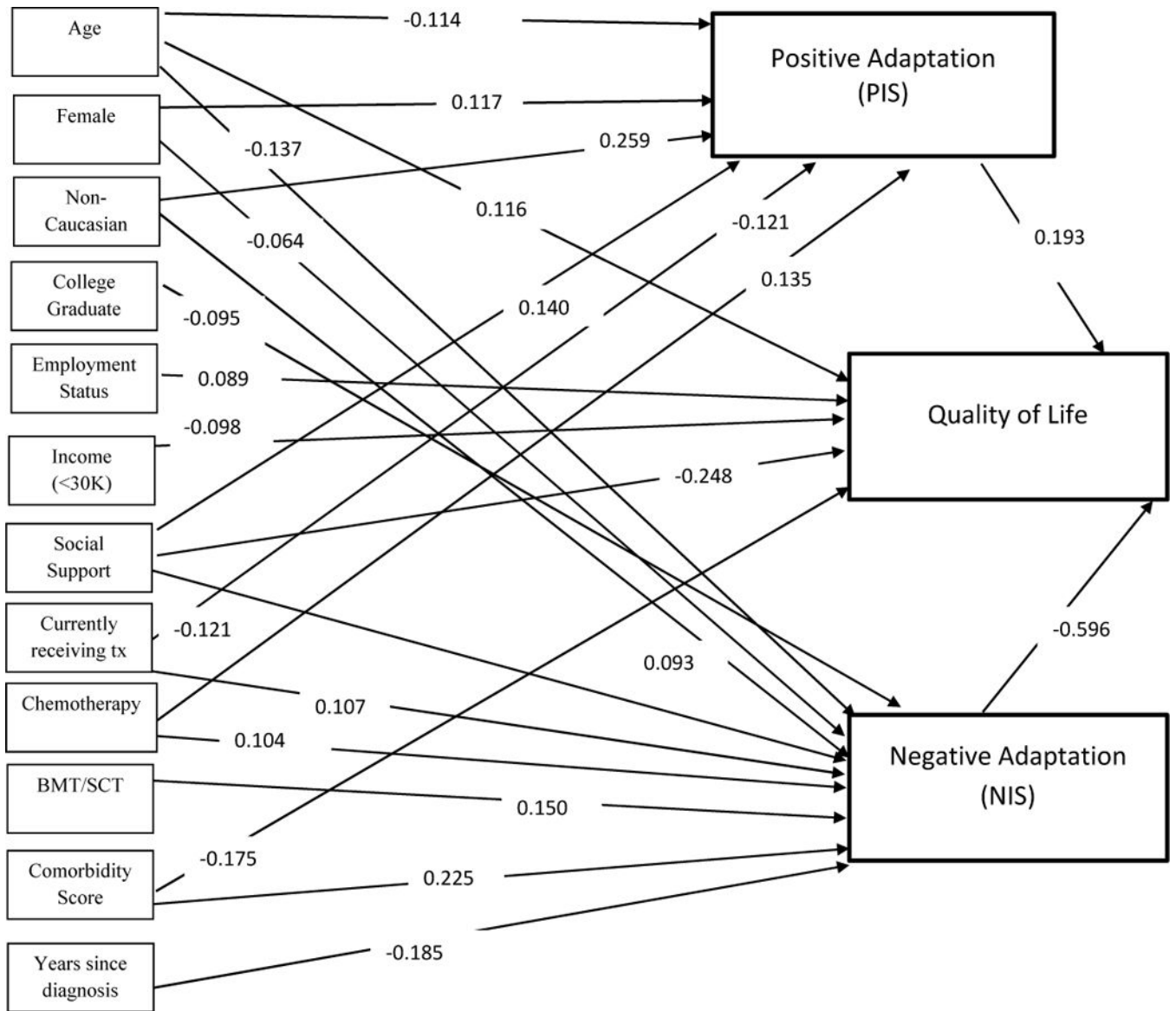*Source*: Adapted from Naus, Ishler, Parrott, and Kovacs, 2009.

Figure 2. Trimmed Cancer Survivor Adaptation Model, Standardized Coefficients (N = 750)
Model Fit: CFI = 0.969, TLI = 0.919, RMSEA = 0.058, SRMR=0.019. All paths were
significant at p<.05

Table 1

Personal Characteristics of the Sample (N=750)

	Frequency	Percent
Endogenous Variables		
QOL	Mean 85.4	Range 10–108
PIS	Mean 3.47	Range 1–5.00
NIS	Mean 2.22	Range 1–4.95
Demographics		
Age	Mean 62.4	Range 26–92
Gender		
Male	379	50.5
Female	371	49.5
Race		
Caucasian	643	85.7
Non-Caucasian	107	14.3
Ethnicity		
Hispanic	12	1.6
Non-Hispanic	738	98.4
Education		
College Graduate	182	24.27
Not a College Graduate	568	75.73
Marital Status		
Married/Living with Partner	575	76.7
Not Married/Living with Partner	174	23.2
Missing	1	0.1
Income ($ annually)		
< 30,000	209	27.8
30,000–59,999	228	30.4
60,000–89,999	132	17.6
90,000 or higher	181	24.1
Disease Factors		
NHL Histology		
Indolent	372	49.6
Aggressive	336	44.8
Missing	42	5.6
Stage at Diagnosis		
I	208	27.6
II	140	18.8
III	123	16.6
IV	182	24.1

	Frequency	Percent
Missing	97	12.9
Currently in Remission		
Yes	586	78.1
No	96	12.8
Don't Know	68	9.1
Currently receiving treatment		
Yes	104	13.8
No	646	86.2
Treatments Received[*]		
Chemotherapy	597	79.6
Radiation Therapy	361	48.1
Biologic Therapy	226	30.1
Surgery	231	30.8
Bone Marrow/Stem Cell Transplantation	119	15.9
Other Therapy	87	11.6
Comorbidity Total Score	Mean 5.6	Range 0–30
Years since Diagnosis	Mean 10.3	Range 2–44
Psychosocial Variables		
Social Support Characteristic	Mean 83.0	Range 20–100
Employment Status		
Retired/Unemployed	432	57.6
Employed	318	42.4

Note.

[*] Percents do not sum to 100 because survivors could have had multiple treatments.

Table 2

Measurement Model using Confirmatory Factor Analysis, Standardized Coefficients (N=750)

Latent Variables and Measures	Mean (SD)	Factor Loadings	Measurement Error Variances	R^2
Quality of Life (QOL)				
Physical Well-being	22.7 (5.5)	0.804	0.354	0.646
Social/Family Well-being	22.2 (5.0)	0.613	0.624	0.376
Emotional Well-being	19.6 (4.0)	0.757	0.427	0.573
Functional Well-being	20.7 (6.0)	0.839	0.296	0.704
Cronbach's alpha=0.812				
Positive Impact Scale (PIS)				
Altruism & Empathy	3.83 (0.94)	0.783	0.386	0.614
Health Awareness	3.67 (0.83)	0.524	0.725	0.275
Meaning of Cancer	2.69 (1.06)	0.708	0.499	0.501
Positive Self-evaluation	3.79 (1.01)	0.771	0.406	0.594
Cronbach's alpha=0.795				
Negative Impact Scale (NIS)				
Appearance Concerns	1.71 (0.90)	0.554	0.693	0.307
Body Concerns	2.41 (1.16)	0.767	0.411	0.589
Life Interferences	1.99 (0.71)	0.817	0.332	0.668
Worry Cronbach's alpha=0.794	2.59 (0.99)	0.668	0.554	0.446

Note: All factor loadings, residual variances, and R^2 values are statistically significant at 0.05 level or lower.

Range for FACT_PWB, FACT_SFWB, FACT_FWB 0–28, and FACT_EWB is 0 to 24.

Range for PIS and NIS subscales are 0 to 5.

Table 3

Decomposition of Effects of Trimmed Path Model, Standardized Coefficients (N=750)

	Direct Effects on QOL	Direct Effects on PIS	Direct Effects on NIS	Indirect Effects on QOL via PIS	Indirect Effects on QOL via NIS	Total Effects on QOL	Mediation Form
Demographics							
Current Age at Study	0.116	−0.114	−0.137	−0.022	0.081	0.175	Partial (both)
Female	–	0.117	−0.064	0.023	0.038	0.061	Full (both)
Non-Caucasian	–	0.259	0.093	0.050	−0.055	−0.005[X]	Full (both)
College Graduate	–	–	−0.095	–	0.057	0.057	Full (NIS)
<30K Annually	−0.098	–	–	–	–	−0.098	None
Disease Factors							
Currently receiving treatment	–	−0.121	0.107	−0.023	−0.064	−0.087	Full (both)
Chemotherapy	–	0.135	0.104	0.026	−0.062	−0.036	Full (both)
BMT/SCT	–	–	0.150	–	−0.089	−0.089	Full (NIS)
Comorbity Score	−0.175	–	0.225	–	−0.134	−0.309	Partial (NIS)
Years since diagnosis	–	–	−0.185	–	0.110	0.110	Partial (NIS)
Psychosocial							
Employment Status	0.089	–	–	–	–	0.089	None
Social Support	0.254	0.140	−0.248	0.027	0.148	0.429	Partial (both)
Adaptation							
PIS	0.193	–	–	–	–	0.193	
NIS	−0.596	–	–	–	–	−0.596	

Note: Positive adaptation (PIS) and negative adaptation (NIS) are the mediators. Variables that were not statistically significant in the trimmed path model were ethnicity, marital status, income greater than $30K, employment status, age at diagnosis, remission status, and certain cancer treatments (e.g., surgery, biologic therapy, radiation therapy). QOL = quality of life, PIS = positive impact scale, NIS = negative impact scale, BMT = bone marrow transplantation, SCT = stem cell transplantation. All other effects are significant at the 0.05 level or lower.

[X] The total effect of being Non-Caucasian is not statistically significant.