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THE ASSOCIATION BETWEEN DISTRESS AND BOTH SOCIAL SUPPORT AND SOCIAL CONSTRAINT IN RECENTLY DIAGNOSED CANCER SURVIVORS: A DAILY ASSESSMENT STUDY

THESIS

A thesis submitted in partial fulfillment of the
requirements for the degree of Master of Science in the
College of Arts and Sciences
at the University of Kentucky

By

Jessica Rivera-Rivera, MPH

Lexington, Kentucky

Director: Dr. Jessica L. Burris, Professor of Psychology

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2017

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ABSTRACT OF THESIS

THE ASSOCIATION BETWEEN DISTRESS AND BOTH SOCIAL SUPPORT AND SOCIAL CONSTRAINT IN RECENTLY DIAGNOSED CANCER SURVIVORS: A DAILY ASSESSMENT STUDY

This study evaluated two distinct aspects of social functioning (specifically, social support and social constraint) in an attempt to increase understanding of its bidirectional relationship with distress after cancer diagnosis. Participants in this intensive longitudinal study were all recently diagnosed, first primary cervical or head/neck cancer survivors (n=47). Data collection involved a comprehensive baseline assessment and 30-day period of daily assessment (n=37) of key variables (i.e., social support, social constraint, and distress). Data were analyzed using unconditional and conditional multilevel linear models. None of the variables changed significantly over the 30-day period. On a typical day, social constraint and distress were predictive of one another (ps < .001). Social support and distress did not demonstrate a bidirectional relationship (ps > .05). In the context of cancer adjustment and survivorship, future interventions for distress should consider targeting social constraint and interventions for social constraint should consider targeting distress.

KEYWORDS**:** Cancer, Distress, Social Support, Social Constraint, Quality of Life

Jessica N. Rivera-Rivera
11/22/2017

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Chapter One: Introduction

Cancer Epidemiology in the United States

Every year, more than 1.5 million people will receive a cancer diagnosis in the United States (American Cancer Society, 2017). In 2016, more than 15.5 million cancer survivors are living in the United States, and this number was expected to grow in 2017 (American Cancer Society, 2017). Based on data from 2007 to 2013, the rate of 5-year survival for all people diagnosed with cancer is 67% (National Cancer Institute, 2017), but it should be appreciated that rates of survival differ significantly across both type (e.g., breast versus lung) and stage (e.g., Stage IA versus IV) of disease. Regardless of an individual's survival rate, the quality of the cancer survivors' life is well recognized as an important outcome to consider.

Quality of Life (QOL)

QOL is a multidimensional concept (Cella & Nowinski, 2002) that includes an individual's perceptions of his or her physical, psychological, spiritual, and social functioning (Ferrell & Hassey Dow, 1997). The aforementioned domains or factors correspond to different aspects of QOL, all of which are theorized to be interdependent (Ferrell & Hassey Dow, 1997). This means that, for example, a change in social functioning is likely to cause or co-occur with a change in psychological functioning, and vice versa. While there is a paucity of longitudinal research that explores the reciprocal relationships among QOL factors (Bloom, Stewart, Johnston, Banks, & Fobair, 2001; Ganz et al., 2003; Hagedoorn, Sneeuw, & Aaronson, 2002; Ramchand, Marshall, Schell, Jaycox, & Corporation, 2008), there is a sizeable body of cross-sectional research that demonstrates significant associations among the factors themselves and/or significant

relationships between overall QOL and its underlying factors (for example, see Cotton, Levine, Fitzpatrick, Dold, & Targ, 1999; Rippentrop, Altmaier, Chen, Found, & Keffala, 2005; Wenzel et al., 2005; Zenger et al., 2010).

Cancer Survivors' QOL

Most research suggests cancer survivors report worse QOL than individuals without a cancer history (Arndt, Merx, Stegmaier, Ziegler, & Brenner, 2004; Burris & Andrykowski, 2011; Jephcott, Paltiel, & Hay, 2004; Lee et al., 2011; LeMasters, Madhavan, Sambamoorthi, & Kurian, 2013; Richardson, Wingo, Zack, Zahran, & King, 2008) though some studies show no significant difference between people with and without a cancer history (Bradley, Rose, Lutgendorf, Costanzo, & Anderson, 2006; Wettergren, Bjorkholm, Axdorph, Bowling, & Langius-Eklof, 2003). Nonetheless, cancer survivors' QOL (see Figure 1.1) is known to vary across individuals and across time (Andrykowski, Lykins, & Floyd, 2008; Helgeson, Snyder, & Seltman, 2004). Some of the individual difference variables that explain QOL differences among cancer survivors include age (Roland, Rodriguez, Patterson, & Trivers, 2013; So et al., 2012), gender (LeMasters et al., 2013), race (Janz et al., 2009), type of diagnosis (Bloom et al., 2001), type of treatment (Zeng, Ching, & Loke, 2011), and behavioral factors (Duijts, Faber, Oldenburg, Beurden, & Aaronson, 2011; Zeng et al., 2011). Although it seems that most cancer survivors' overall QOL improves with time – even if it does not return to their pre-cancer baseline (Andrykowski et al., 2008; Hsu, Ennis, Hood, Graham, & Goodwin, 2013) – the sub-factors of QOL can show a different pattern of change or no change at all (Hsu et al., 2013; Koczywas et al., 2013; So et al., 2012). Thus, the QOL of cancer survivors is quite complex.

The large body of research on cancer survivors' QOL includes studies that focus on describing the nature and course of one or more individual factors. The literature shows that cancer survivors' overall physical functioning (e.g., nausea, fatigue, and sleep problems) may improve after treatment (Bloom, Petersen, & Kang, 2007), but some late effects of treatment (e.g., cognitive impairment, pain, and cardiovascular events) can occur in this population (Ahles et al., 2002; Kenyon, Mayer, & Owens, 2014). Physical functioning is often correlated with psychological functioning (Loeb & Jonas, 2015; Ramchand et al., 2008; Wilson & Cleary, 1995), which includes symptoms of anxiety, depression, and other indicators of distress [1] as well as positive outcomes like life satisfaction (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998; Wilson & Cleary, 1995). Psychological functioning is also known to change over time (Bloom et al., 2007; Stiegelis, Ranchor, & Sanderman, 2004), a finding that will be discussed in more depth later. Spiritual functioning pertains to the ability to derive meaning from the cancer experience, be hopeful, and perceive a sense of purpose in life (Brady, Peterman, Fitchett, Mo, & Cella, 1999; Ferrell et al., 1998; Sterba et al., 2014; Wenzel et al., 2005). A study of lung cancer survivors' spiritual needs found that it fluctuates in the last year of life, and that spiritual distress is greatly associated with four key events along the cancer continuum (specifically, diagnosis, treatment completion, disease progression, and terminal illness; Murray et al., 2007). Although this study only included lung cancer

[1] The National Comprehensive Cancer Network defines "distress" as "a multifactorial unpleasant *emotional* experience… that may interfere with the ability to cope effectively with cancer, its physical symptoms and its treatment" (National Comprehensive Cancer Network, 2013, pg. DIS-3, emphasis added). As "distress" and "psychological distress" are viewed here as interchangeable, "distress" will be used for sake of brevity.

survivors, it is likely the results may generalize to other cancer survivors. Finally, social functioning primarily deals with an individual's social roles and relationships (Bloom et al., 2007; Ferrell, Grant, Funk, Otis-Green, & Garcia, 1997). Social-related concerns (e.g., worry about finances or job security, or fear about one's daughter developing cancer) may persist beyond the completion of cancer treatment (Beckjord et al., 2014; Ferrell et al., 1997), and may differ by gender, age, race, and ethnicity (Bourjolly, Kerson, & Nuamah, 1999; Carver, Smith, Petronis, & Antoni, 2006; Hammerlid & Taft, 2001). Although prior research largely treats the various QOL factors as unique, it is expected that disruption or improvement in one factor will affect one or more of the others factors (Bloom et al., 2007), a dynamic relationship that can only be fully tested by use of longitudinal research designs.

Compared to the physical and psychological aspects of cancer survivors' QOL, the spiritual and social aspects have received little attention. In particular, social functioning deserves greater clinical and research attention since cancer is a disease that affects the whole family, not just the individual who receives the diagnosis (Ballard-Reisch & Letner, 2003; Edwards & Clarke, 2004; Mantani et al., 2007; Traa, De Vries, Bodenmann, & Den Oudsten, 2015). Another reason to better understand the social functioning of cancer survivors is because it could explain (at least in part) why other aspects of QOL, such as psychological functioning, vary across people and time. Given the fact that social functioning is a relatively understudied, but potentially influential factor for cancer survivors, it will be the focus herein.

Social Functioning I

Social functioning corresponds to a wide array of social components (e.g., occupation/workplace productivity, community engagement, relationship quality, and parental, familial, and other social roles; Hirschfeld et al., 2000), and is related to how individuals interact with the environment and engage in social relationships (Bosc, 2000). Among cancer survivors, various indicators of social functioning demonstrate the ability to impact both health behavior and QOL outcomes (Edwards & Clarke, 2004; Pasipanodya et al., 2012; Roland et al., 2013). To summarize, studies with cancer survivors that show better social functioning is associated with better treatment adherence (DiMatteo, 2004), higher levels of physical activity (Mosher et al., 2009), less distress (Jim & Andersen, 2007; Mantani et al., 2007; Roland et al., 2013), less physical pain (Roland et al., 2013), and better overall health (Roland et al., 2013). Although social functioning appears to have a strong influence on important outcomes among cancer survivors, a closer look at the extant research shows some inconsistency across studies. Some studies have found that cancer survivors have poorer social functioning than the general population (Arndt et al., 2004; Efficace et al., 2008; Vironen, Kairaluoma, Aalto, & Kellokumpu, 2006) while other studies have not found this difference (Dorval, Maunsell, Deschbnes, Brisson, & Masse, 1998; McLarty et al., 1997; van Tulder, Aaronson, & Bruning, 1994; Wenzel et al., 2005). Similarly, some studies find social functioning improves with time (Chan, Ng, Ngan, & Wong, 2003; King, Kenny, Shiell, Hall, & Boyages, 2000) while others do not (Bozec et al., 2008; de Graeff et al., 2000b; Ronis, Duffy, Fowler, Khan, & Terrell, 2008). Finally, some studies find social functioning is associated with the overall QOL of cancer survivors (Edwards & Clarke,

2004; Karnell, Christensen, Rosenthal, Magnuson, & Funk, 2007; Pasipanodya et al., 2012; Roland et al., 2013; Wenzel et al., 2005), whereas other studies do not find a significant association between these variables (Kemmler et al., 1999; King et al., 2000). A plausible explanation for all of this inconsistency is that social functioning is a multidimensional construct that includes a wide range of domains, not all of which operate in the same way or carry the same significance across outcomes (Muzzatti & Annunziata, 2012).

Since social functioning is multidimensional and its various sub-components may differentially impact any and all outcomes of interest (Hirschfeld et al., 2000), the proposed study will focus not on the broader construct, but on two sub-components thought to be particularly important for cancer survivors. Herein, the focus is on the social factors of social support and social constraint. By focusing on these factors, the proposed study will address both a positive and negative dimension of social functioning (social support and social constraint, respectively), and provide important information about which specific aspects of social functioning explain the distress of cancer survivors.

Social Functioning II: Social Support

Definitions and measurement. Social support is normally considered a positive dimension of social functioning (Mallinckrodt, Armer, & Heppner, 2012; Nilsson et al., 2013). Although social support does not have a universally agreed upon definition (Uchino, 2006; Walsh & Connelly, 1996), it may be understood as the emotional, instrumental, and informational support provided by an individual's social network (Dakof & Taylor, 1990). In addition, in some studies, social support is divided into

structural and functional support, where structural support refers to the number of people in ones social network and functional support refers to the nature, quality, and function of the support components (Nausheen, Gidron, Peveler, & Moss-Morris, 2009). The aforementioned variability in definitions and measurement of social support likely contributes to a lack of consensus concerning how, for whom, and when social support influences other aspects of QOL or any other outcome (Nausheen et al., 2009; Uchino, 2006). For example, perceived social support in long-term cancer survivors is sometimes, but not always related to posttraumatic growth (Schroevers, Helgeson, Sanderman, & Ranchor, 2010), and lower perceived social support is more strongly related to colon cancer risk in African American men than Caucasian men (Kinney et al., 2003). The proposed study will focus on the amount of perceived functional social support since 1) it is most consistently related to various aspects of QOL (Luszczynska, Pawlowska, Cieslak, Knoll, & Scholz, 2013) and 2) it has a broad research base from which to make firm hypotheses.

Significance. Social support is positively linked to physical functioning (Luszczynska et al., 2013) and treatment adherence (Spiegel, 1997), and negatively related to cancer progression (Nausheen et al., 2009). Social support also seems to help cancer survivors cope with anger, stress, depression, and other indicators of psychological maladjustment (Holland & Holahan, 2003; Jim & Jacobsen, 2008; Koopman, Hermanson, Diamond, Angell, & Spiegel, 1998; Luszczynska et al., 2013; Nausheen et al., 2009; Salonen et al., 2012; Turner-Cobb, Sephton, Koopman, Blake-Mortimer, & Spiegel, 2000). It is also related to workplace productivity, an outcome which may reflect a “return to normal” after cancer diagnosis (Nilsson et al., 2013).

Finally, greater social support predicts better overall QOL (Salonen et al., 2012; So et al., 2012). In sum, social support is an important predictor of several essential outcomes in cancer survivors, including QOL.

Social Functioning III: Social Constraint

Definitions and measurement. In contrast to social support, social constraint reflects a negative aspect of social functioning. Lepore and Revenson (2007) define social constraint as "both objective social conditions and individuals' construal of those conditions that lead individuals to refrain from or modify their disclosure of stress- and trauma-related thoughts, feelings, or concerns" (pg. 3). Social constraint is present when someone has an unsupportive partner, friend, or family member that responds negatively with criticism, avoidance, or conflict (Badr & Carmack Taylor, 2006). Of note, social constraint can be present in what is perceived to be a generally supportive relationship (Kratz et al., 2010; Pasipanodya et al., 2012), and it may even happen unintentionally (Pasipanodya et al., 2012). For example, a caregiver can behave in a way intended to communicate openness and interest, but the cancer survivor does not perceive it as such (Pasipanodya et al., 2012). Since social constraint can exist within the context of a generally positive relationship, it is important that studies of social support also measure social constraint. Unlike the research on social support, there is one measure of social constraint that is widely used across studies on the topic: the Social Constraints Scale (Adams, Winger, & Mosher, 2015; Lepore & Ithuarte, 1999; Lepore & Revenson, 2007; Pasipanodya et al., 2012). The proposed study will therefore measure social constraint with the aforementioned scale, so the results of this study can more easily be compared to those from prior studies with cancer survivors.

Significance. Within the context of any relationship, people who experience social constraint are less likely to share the events of their daily life (Pasipanodya et al., 2012) and therefore compromise their cognitive and emotional processing of particularly stressful events (Badr & Carmack Taylor, 2006; Lepore & Revenson, 2007). Thus, social constraint may negatively impact both individual well-being and the quality of ones relationship with others (i.e., relational well-being; Edwards & Clarke, 2004; Lepore & Revenson, 2007; Pasipanodya et al., 2012). In cancer survivors, social constraint has negative implications for self-esteem (Pasipanodya et al., 2012), and some indicators of distress (Cordova, Cunningham, Carlson, & Andrykowski, 2001), and it is expected to have a detrimental impact on overall QOL.

Psychological Functioning I

Like social functioning, psychological functioning is a complex, multidimensional construct (Andrykowski et al., 2008; Ferrell et al., 1998). After cancer diagnosis, it is expected that most individuals will experience some degree of psychological disturbance (Andrykowski et al., 2008). In many cases, cancer survivors' psychological functioning is expected to improve over time (Andrykowski et al., 2008; Helgeson et al., 2004). For those who experience an improvement, three outcomes are possible: 1) a return to a pre-cancer baseline, or "recovery", 2) an overall decrease in psychological functioning compared to the pre-cancer baseline, or "impairment", and 3) an overall increase in psychological functioning compared to the pre-cancer baseline, or "growth" (Andrykowski et al., 2008). Thus, the psychological functioning of cancer survivors can follow any number of paths, some reflecting positive change, others reflecting negative change, and still others reflecting no change at all (i.e., "resilience").

Psychological functioning includes positive and negative aspects, and it is important to note that said aspects are not mutually exclusive (Cordova et al., 2001). As a higher-order construct, psychological functioning is related to subjective reports of both health status (Ganz et al., 2003) and overall QOL (Tomich & Helgeson, 2012; Wenzel et al., 2005; Zenger et al., 2010). The positive dimensions of psychological functioning correspond to reports of enhanced psychological adjustment and well-being, which are often subsumed by the concept of posttraumatic growth (Andrykowski et al., 2008). Other positive psychological outcomes include benefit finding, happiness, self-esteem, and life satisfaction (Andrykowski et al., 2008). While such positive outcomes are indeed possible and clinically significant after cancer diagnosis, most research focuses on the negative aspects of psychological functioning. Negative psychological functioning mostly corresponds to reports of distress, which includes the outcomes of anxiety, worry, depression, sadness, anger, fear, and panic (Andrykowski et al., 2008; Ferrell et al., 1998). Since distress is a common experience for many cancer survivors (for reviews, see Andrykowski et al., 2008; Carlson, Waller, & Mitchell, 2012; Jim & Jacobsen, 2008; Walker et al., 2012), and it too has clinically significant implications for cancer survivors (Andersen et al., 2008; Greer, Pirl, Park, Lynch, & Temel, 2008; Weitzner, Meyers, Stuebing, & Saleeba, 1997; Zenger et al., 2010), the focus of the proposed study is on distress.

Psychological Functioning II: Distress

Definitions and measurement. The experience of cancer – from diagnosis through treatment, recovery, and end-of-life – is widely accepted as a chronic stressor, and as such, it is common for cancer survivors to experience some degree of distress at some

point along the continuum of care (Andrykowski et al., 2008; Carlson et al., 2012). Distress ranges from normal feelings of vulnerability and sadness to problems that becomes disabling (National Comprehensive Cancer Network, 2013). There are a multitude of distress measures in the literature, many of which are commonly used with cancer survivors (e.g., Brief Symptom Inventory, General Health Questionnaire, and Distress Thermometer; Carlson et al., 2012). The Distress Thermometer – a single-item scale that taps overall distress (National Comprehensive Cancer Network, 2013) – is one of the most widely recommended for use with cancer survivors due to its simplicity, brevity, and predictive value (Carlson et al., 2012). Consequently, the proposed study will use the Distress Thermometer.

Significance. A diagnosis of cancer increases the likelihood that someone experiences distress, even if that distress is time-limited. Around 35% of cancer survivors experience high levels of distress, with variation in the prevalence of "clinically significant" distress across the various types of cancers (Zabora, Brintzenhofeszoc, Curbow, Hooker, & Piantadosi, 2001). Among cancer survivors, distress has a detrimental impact on treatment compliance (DiMatteo, Lepper, & Croghan, 2000), number of medical visits (i.e., more visits), and cost of medical care (i.e., higher costs; Carlson & Bultz, 2004). Furthermore, distress predicts or is correlated with poorer social functioning (Badr, Laurenceau, Schart, Basen-Engquist, & Turk, 2010; Pasipanodya et al., 2012; Zakowski et al., 2003) and overall QOL in cancer survivors (Brown, Kroenke, Theobald, Wu, & Tu, 2010; Weitzner et al., 1997; Zenger et al., 2010). Due to its high prevalence and significance, more research should explore modifiable risk and protective factors for distress.

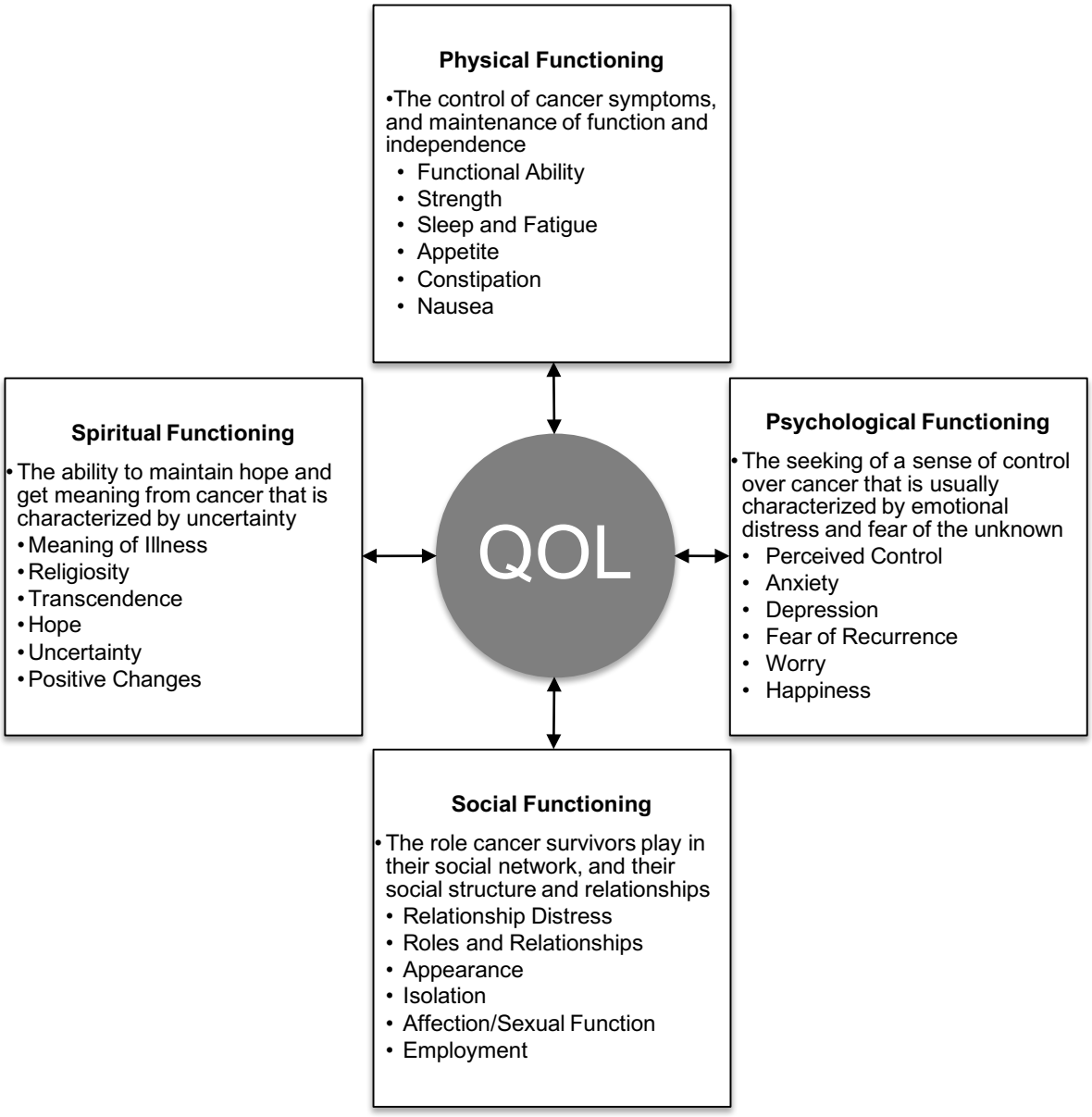
Current Study Aims

Aim 1. Measure and describe change over time in the social functioning and distress of recently diagnosed cancer survivors. Three hypotheses correspond to this aim: a) social support will decline significantly over time; b) social constraint will not change significantly over time, and c) distress will not change significantly over time.

Aim 2. Examine whether there is a longitudinal, bidirectional relationship between social functioning and distress in recently diagnosed cancer survivors. Three hypotheses correspond to this aim: a) greater social support will predict lower levels of distress, b) greater social constraint will predict higher levels of distress, and c) greater distress will predict lower levels of support and higher levels of social constraint.

Figure 1

Quality of Life in Cancer Survivors (adapted from Ferrell, Dow & Grant, 1995)



Chapter Two: Methods

Participants

Participants were adults with recently diagnosed, first primary cervical or head/neck cancer (n=47). Since this study is part of a larger study of tobacco use after a new cancer diagnosis, all participants were current tobacco users based on 30-day point prevalence at study enrollment. Other inclusion criteria were as follows: 1) pathology-confirmed cervical cancer or head and neck squamous cell carcinoma; 2) cancer diagnosis in the 6 months prior to enrollment; 3) age 21 or older at enrollment; and 4) ability to read, write, and understand English. Exclusion criteria were: 1) prior cancer diagnosis other than non-melanoma skin cancer; 2) cognitive or psychiatric impairment that would interfere with the ability to provide informed consent or complete study procedures; 3) unreliable phone access (i.e., no landline or cellular phone for personal use); and 4) pregnancy or plan to be pregnant within 6 months.

Procedure

Recruitment and enrollment. Participants were recruited through the University of Kentucky Markey Cancer Center in Lexington, KY. Participants with cervical and head/neck cancer were recruited through the Gynecologic Oncology Clinic and Multidisciplinary - Head and Neck Clinic, respectively. In consultation with attending oncologists and nurses, research staff accessed and reviewed the electronic medical records of individuals scheduled for an initial evaluation to conduct a preliminary screen for eligibility. Those individuals not ruled out on the basis of information in their electronic medical record were then screened for eligibility either in person or over the phone. Eligible persons were briefly informed about the study procedures and asked if they would like to participate. If interested in study participation, these persons began the

process of informed consent. Individuals were "enrolled" into the study upon attainment of written informed consent and a signed HIPAA authorization. Prior to the implementation of this study, it was approved by the UK Institutional Review Board.

Baseline assessment. Shortly after enrollment, a baseline assessment was conducted. Participants had the option to complete the baseline assessment via a paper-and-pencil questionnaire (mail) or interview with research staff (over the phone or in-person). If the questionnaire format was used for this assessment, participants received and returned the questionnaire by mail at no cost to them. The phone interview format was assisted by Research Electronic Data Capture (REDCap, Harris et al., 2009), and the in-person interviews were administered in clinic. Most participants completed this assessment via questionnaire (68.09%, n=32), with 17.02% (n=8) completing it by phone, and 14.89% (n=7) completing it in-person. Regardless of the method of data collection, the baseline assessment took 30-45 minutes to complete, and all data were entered and stored securely in a REDCap database.

Daily assessment. After the baseline was completed, participants were scheduled to begin a 30-day period of daily assessment (i.e., 30 consecutive days of assessment). The preferred mode of data collection for this assessment was via phone. Instead of a conventional phone interview that requires interaction with research staff, the daily assessment was administered through the use of an interactive voice response (IVR) system, which is described in more detail below. IVR is an optimal approach to data collection since the data are securely collected and stored with a date and time stamp all in real time. Additionally, IVR can be used with any phone without the need for a new device or modification of an existing device (as is the case with some methods of daily

assessment, such as ecological momentary assessments). Finally, IVR has good acceptability and satisfaction among consumers (Corkrey & Parkinson, 2002; Mundt, 1997), in part because it is viewed as more confidential than standard interviews (Corkrey & Parkinson, 2002; Kobak, Greist, Jefferson, & Katzelnick, 1996). In sum, IVR provides a reliable and valid means of data collection within an ecological framework.

The IVR system used for this study was proactive, which means participants received an automated call at the same time each afternoon or evening, with the precise time dependent upon the preference of a given participant. If participants did not answer the call, the IVR system tried again two more times that same day according to a pre-set schedule of calls. Furthermore, participants also had the option to call into the IVR system via a 1-800 toll-free number in order to complete an assessment missed earlier in the day, or to proactively complete an assessment they would otherwise miss (e.g., if social plans conflict with their regular call schedule). The assessment itself consisted of 20 questions in total, only five of which were of relevance to the proposed study (see "Daily assessment" in the Measures section below). In its entirety, this assessment took 5.72 ± 1.09 ($M \pm SD$) minutes to complete. During the call, participants responded to the IVR system via their phone's keypad, and were able to repeat any question as needed before responding.

As with the baseline assessment, participants had the option to complete this assessment via a paper-and-pencil questionnaire. Once again, if this format was used, participants received and returned the questionnaires by mail at no cost to them. Data obtained via questionnaire was entered and stored securely in the same system used for data collected via phone. While the use of a paper questionnaire is not ideal for daily

assessments, it was used here in an attempt to lessen the amount of missing data due to reasons unrelated to the research question (i.e., the practical challenges of coping with a chronic disease, rigorous medical procedures, and possibly even hospitalization during the course of the daily assessments). In the end, just under half of the daily assessments were completed via phone (44.73%, *n*=395).

Compensation. Participants received $20 for completion of the baseline assessment. The compensation rate for the daily assessment was consistent with prior, similar studies and was designed to increase compliance with study procedures (Helzer, Badger, Rose, Mongeon, & Searles, 2002; Hughes et al., 2013; Peters & Hughes, 2009; Searles, Helzer, Rose, & Badger, 2002; Tucker et al., 2007). Thus, participants were paid $2 for each assessment and an additional $5 for each week where all assessments were completed; participants received compensation on a weekly basis for these assessments in order to maintain interest in this aspect of the study. In total, participants could earn up to $80 for the daily assessment. For both types of assessments, participants were paid via check.

Measures

Demographics. Standard items for assessment of demographic background (e.g., age, race, and relationship status) were used. Items were largely taken verbatim from the Behavioral Risk Factors Surveillance System survey (Centers for Disease Control and Prevention, 2011), which is a population-based health survey done annually in the United States.

Chart review. A review of each participant's electronic medical record at the University of Kentucky was done in order to describe the clinical characteristics of the

sample. These variables were extracted from each medical record, if available: 1) date of diagnosis; 2) age at diagnosis; 3) cancer site (e.g. larynx, oral cavity, cervical, etc.); 4) cancer stage; 5) date of treatment initiation; and 6) nature of treatment (e.g., surgery, radiation).

Social support. Social support at baseline was primarily measured with the Duke-UNC Functional Social Support Questionnaire (SSQ; Broadhead, Gehlbach, de Gruy, & Kaplan, 1988), as it taps the dimensions of perceived affective support (e.g., support obtained from people who give affection) and confidant support (e.g., support obtained through opportunities to talk about personal problems and participate in activities). The SSQ is often used in studies with cancer survivors (e.g., Breitbart et al., 2000; Broadhead & Kaplan, 1991; Bultz, Speca, Brasher, Geggie, & Page, 2000; Herndon et al., 1999; Osborne & Sinclair, 2004), which added to its suitability for this study. The 8-item SSQ has good construct, concurrent, and discriminant validity, and is sensitive to change over time (Broadhead et al., 1988). Example items include: "I get chances to talk to someone I trust about my personal and family problems" and "I get invitations to go out and do things with other people." All items are measured on a scale from 1=*much less than I would like* to 5=*as much as I would like*. Items are scored such that higher total scores on the SSQ reflect greater perceived social support, and total score range from 8 to 40. The coefficient alpha for the SSQ was 0.92.

In addition to the SSQ, participants were asked to identify the one person in their life who they consider to be their main source of support. Response options included: 1) spouse or other romantic partner; 2) child; 3) other family member; 4) close friend; 5) member of religious organization; 6) neighbor; 7) other individual; or 8) no one ("I

cannot think of a support person right now"). This last question is unique to the proposed study, and was only used for descriptive purposes.

Social constraint. The 15-item Social Constraints Scale (SCS; Lepore & Ituarte, 1999) was used to measure social responses that inhibit the expression of cancer-related thoughts, feelings, and experiences at baseline. This measure is the most valid and commonly used indicator of social constraint in studies with cancer survivors (for a review, see Adams et al., 2015; Lepore & Revenson, 2007). Instructions for the SCS directed participants to consider the behavior of other in the past month, specifically "with regard to [their] experience with cancer diagnosis and treatment." Example items include: "Minimize your problems," "Act uncomfortable when you talked about your experiences," and "Tell you not to worry so much about your health." All items were measured on a scale from 1=never to 4=often. Items were scored such that higher scores indicate greater social constraint, total score ranges from 15 to 60. Coefficient alpha for the total score was 0.92.

Distress. Since distress presents in many ways, two measures of distress were used at baseline: 1) a modified Distress Thermometer (DT) and 2) the Hospital Anxiety and Depression Scale (HADS). Both of these measures are discussed below.

The 1-item DT (National Comprehensive Cancer Network, 2013), which is commonly used with cancer survivors (e.g., Bevans et al., 2008; Chambers et al., 2013; Hegel et al., 2008; Jacobsen et al., 2005), captures global distress on a 0 to 10 scale. Distress in cancer survivors tends to change over time, and changes in DT scores are positively correlated to changes in related measures (Gessler et al., 2008). Furthermore, DT scores demonstrate good sensitivity and specificity when measured against other self-

report measures or structured clinical interviews (Chambers, Zajdlewicz, Youlden, Holland, & Dunn, 2014; Jacobsen et al., 2005; Patel, Sharpe, Thewes, Bell, & Clarke, 2011). In addition to continuous scores, a score of ≥4 is typically used as a cut-off to identify which cancer survivors may have clinically significant distress (Chambers et al., 2014; Gessler et al., 2008; Jacobsen et al., 2005; Patel et al., 2011). The original measure asks about distress experienced in the past week, but in the proposed study, participants were only asked to consider their experiences on the day of the assessment. Additionally, the DT used in this study is on a 0 to 9 scale in order to be consistent with other items in the IVR assessment protocol. The item read as follows: "On a scale from 0 to 9, where 0 is no distress and 9 is extreme distress, how much distress did you experience today?" The 14-item HADS (Zigmond & Snaith, 1983) measures anxiety and depressive symptoms, and it too is often used with cancer survivors (e.g., Patel et al., 2011; Sellick & Edwardson, 2007; Stafford et al., 2014). HADS anxiety and depression subscales have good reliability and validity (Bjelland, Dahl, Haug, & Neckelmann, 2002). In cancer survivors, the sensitivity and specificity for the anxiety, depression, and total scales falls between 70% and 90% (Bjelland et al., 2002; Patel et al., 2011; Stafford et al., 2014; Jane Walker et al., 2007). On the HADS, participants were asked to what extent each item (or symptom) describes their feelings in the past week. Example items for anxiety and depressive symptoms are "Worrying thoughts go through my mind" and "I have lost interest in my appearance," respectively. All items were answered on a scale from 0 to 3, with the exact response option dependent upon the item. Items were scored such that higher scores represent more severe anxiety and depressive symptoms. In addition to continuous scores, cut-off scores can be used to identify clinically significant distress in

cancer survivors, with cut-off scores that range from 7 to 11 for the depression and anxiety subscales (Bjelland et al., 2002; Walker et al., 2007); in this study, a score ≥11 was used as a cut-off. Coefficient alpha for the HADS total score was 0.89, and coefficient alpha for the anxiety and depression subscale scores were 0.85 and 0.80, respectively.

Daily assessment. The daily assessment consisted of five face valid items that as a whole cover all key study variables (i.e., social support, social constraint, and distress). Each item asked about participants' experience the day of the assessment. Additionally, all items were measured on a 0 to 9 scale; higher scores indicate more social support (the only favorable outcome), more social constraint, and more distress. Social support and social constraint were each measured with a single item while distress was measured with three items that separately tap global distress, anxiety, and depressive symptoms (see Table 2.1). The 1-item DT was used to measure distress in the daily assessment. Each of the others items used in the daily assessment were adapted from, and/or reflects the basic idea within, the more comprehensive measures described above.

Although it is generally preferred to use multi-item measures to assess complex psychosocial constructs, daily assessment studies require brevity for compliance. The items in this study, therefore, converge with the approach used in similar daily assessment studies (e.g., (Searles et al., 2002; Zhou et al., 2009). To evaluate how well the single items related to their corresponding multi-item measures at baseline, Pearson's r bivariate correlations were conducted. The single-item measures for social support (r=.54, p<.001), anxiety symptoms (r=.73, p<.001), and depressive symptoms (r=.58, p<.001) all exhibited strong and positive associations with their respective multi-item

measures. In contrast, while the single-item social constraint measure was significantly and positively correlated with its corresponding multi-item measure, the strength of the relationship was relatively weak (r=.31, p=.04). Finally, and as noted above, there was not a multi-item measure of distress available for comparison with the modified DT.

Data Analysis

Basic descriptive statistics (e.g., means, frequencies) and preliminary analyses (e.g., bivariate Pearson's r correlations) were used to describe the sample's basic characteristics and the relationships among all study variables at baseline. Statistical analysis focused on data collected via the daily assessment.

As expected, missing data were present in the daily assessment due to the high demand of study participation (i.e., daily assessments for one month) and the nature of participants in the study (i.e., recently diagnosed cancer survivors undergoing and/or recovering from arduous treatments). As a result, the possibility of bias was analyzed by exploring baseline group differences on key study variables between participants with (78.72%, n=37) and without (21.28%, n=10) daily assessment data; independent samples t-tests and chi-square analyses were conducted, as appropriate. No significant differences were found on any measure of participants' demographic background (Table 2.2), clinical characteristics (Table 2.3), social functioning (Table 2.4), or distress (Table 2.4). To explore whether there were significant differences across participants who completed varying amounts of the daily assessment, t-tests and chi-square analyses were again conducted, as appropriate. With only one exception, no significant differences were found on any of the aforementioned measures (data not shown). The exception was for

the single-item anxiety measure: participants with higher anxiety levels completed a smaller number of assessments (p=.04).

For the primary analyses, multilevel modeling was used due to the nature of intensive longitudinal data (Bolger & Laurenceau, 2013; Singer & Willett, 2003). For Aim 1, slopes of change in social functioning (i.e., social support and social constraint) and distress from the first to the last day of the daily assessment were examined using a series of unconditional random intercept and slope multilevel linear models. Linear models were chosen because visual depiction of the raw data was not strongly suggestive of a curvilinear pattern of change. For ease of interpretation, the first day of daily assessment data was coded as zero (days coded as 0 – 29). For Aim 2, conditional multilevel linear models were used to identify the bidirectional relationship between day-to-day changes in social functioning and distress. In these models, if a predictor variable's slope of change did not significantly differ across the 30 days, person-centered means scores on the predictor were used in the model. Further, if the dependent variable's slope did not change significantly over time in the unconditional models, time was re-centered at the mid-point of the daily assessment (i.e., day 15) to establish a "typical day" for the dependent variable. For both aims, restricted maximum likelihood estimation was used to handle missing data, and data analysis was done with version 24 of the Statistical Package for the Social Sciences (SPSS) (IBM Corp., 2017).

Table 2.1

Daily Assessment Measures

Variable	Item	Scale
Social Support	"How much support did you receive from others today?"	0=none to 9=a great deal
Social Constraint	"How often did others dismiss your concerns when you tried to express them today?"	0=never to 9=almost all the time
Distress		
Global distress	"How much distress did you experience today?"	0=no distress to 9=extreme distress
Anxiety symptoms	"How often did you feel worried, tense, or anxious today?"	0=never to 9=almost all the time
Depressive symptoms	"How often did you feel sad, blue, or depressed today?"	0=never to 9=almost all the time

Table 2.2

Demographic Characteristics of the Sample

Variables	Total sample (*n*=47)	Daily assessment data		p
		Yes (*n*=37)	No (*n*=10)	
Age in years [1]	56.43 ± 7.42	55.89 ± 8.01	58.40 ± 4.43	.35
Gender				
Male	63.83	59.46	80.00	.23
Female	36.17	40.54	20.00	
Race				
White, non-Hispanic	95.74	94.59	100.00	.75
African American	2.13	2.70	0.00	
Hispanic/Latino	0.00	0.00	0.00	
Other	2.13	2.70	0.00	
Relationship status				
Single, never married	8.51	8.11	10.00	.89
Divorced, widowed, separated	44.68	43.24	50.00	
Married or partnered	46.81	48.65	40.00	
Educational attainment				
Less than high school graduate or equivalent	34.04	32.43	40.00	.87
High school graduate or equivalent	40.43	40.54	40.00	
Some college or college graduate	25.53	27.03	20.00	
Employment				
Employed	21.28	21.62	20.00	.92
Unemployed	12.77	13.51	10.00	
Disabled	51.06	48.65	60.00	
Other [2]	14.89	16.22	10.00	
Annual household income				
Less than $10,000	40.43	40.54	40.00	.72
$10,000 to $19,999	27.66	24.32	40.00	
$20,000 to $34,999	19.15	21.62	10.00	
$35,000 or more	12.77	13.51	10.00	

Note. Data are percentages unless otherwise noted. Percentages may not sum to 100.0 due to rounding. [1] Data are means ± standard deviations. [2] Other denotes homemaker, student, or retired.

Table 2.3

Clinical Characteristics of the Sample

Variable	Total Sample (*n*=47)	Daily Assessment Data		*p*
		Yes (*n*=37)	No (*n*=10)	
Months since diagnosis [1]	1.11 ± 1.71	1.27 ± 1.88	0.50 ± .53	.21
Months since treatment [1]	0.32 ± 1.42	1.05 ± 1.51	0.25 ± .50	.31
Cancer site				
Cervical	12.77	16.22	0.00	.60
Oral Cavity	10.64	8.11	20.00	
Larynx	34.04	32.43	40.00	
Nasal Cavity	8.51	8.11	10.00	
Pharynx	27.66	27.03	30.00	
Sinus	6.38	8.11	0.00	
Histology				
Squamous cell carcinoma	97.87	97.30	100.00	.60
Adenocarcinoma [2]	2.13	2.70	0.00	
Cancer stage				
0 or In situ	4.44	5.56	0.00	.53
I	13.33	13.89	11.11	
II	15.56	19.44	0.00	
III	15.56	13.89	22.22	
IV or metastatic	51.11	47.22	66.67	
Treatment received				
Yes	91.50	94.44	90.00	.61
No	4.26	2.78	10.00	
Not started yet treatment	4.26	2.78	0.00	
Treatment type [3]				
Surgery only	16.28	17.65	11.11	.75
Radiation only	9.30	11.76	0.00	
Surgery and radiation or chemotherapy	13.95	11.76	22.22	
Radiation and chemotherapy	41.86	41.18	44.44	
Surgery, radiation, and chemotherapy	18.60	17.65	22.22	

Note. Data are percentages unless otherwise noted; [1] Data are means ± standard deviations. [2] Only applicable to cervical cancer. [3] Data are for participants whose treatment was documented in their medical record at the time of data analysis (*n*=43).

Table 2.4

Descriptive Information for Key Study Variables

Variables	Total Sample (*n*=47)	Daily Assessment Data		*p*
		Yes (*n*=37)	No (*n*=10)	
Multi-item measures				
Social Support	31.25 ± 9.00	31.54 ± 9.09	30.11 ± 9.06	.68
Social Constraint	30.22 ± 11.01	29.31 ± 10.42	33.78 ± 13.15	.28
HADS Total	14.37 ± 8.54	13.24 ± 8.04	19.00 ± 9.49	.07
Anxiety	7.91 ± 5.01	7.22 ± 4.92	10.78 ± 4.55	.06
Depression	6.49 ± 4.36	6.03 ± 4.04	8.20 ± 5.27	.17
Single item measures				
Social Support	5.45 ± 3.50	5.89 ± 3.50	3.80 ± 3.12	.09
Social Constraint	2.32 ± 3.35	2.65 ± 3.62	1.10 ± 1.66	.20
Distress	4.32 ± 2.96	4.49 ± 2.98	3.70 ± 2.95	.46
Anxiety	4.38 ± 3.31	4.35 ± 3.22	4.50 ± 3.84	.90
Depression	3.57 ± 3.49	3.49 ± 3.53	3.90 ± 3.51	.74

Note. Data are means ± standard deviations.

Chapter Three: Results

Preliminary Analyses

Sample demographic and clinical characteristics. A total of 47 participants completed the baseline assessment, and the details of their demographic and clinical background can be found in Tables 2.2 and 2.3. As a brief summary, participants' average age was 56.43 ± 7.42 years old. Most participants were male (63.83%, *n*=30) and identified themselves as White non-Hispanic (95.74%, *n*=45). Just under half of the participants reported being in a relationship (46.81%, *n*=22). The educational attainment of the sample was low, with only 25.53% (*n*=12) reporting college education. Related to their employment status, most participants reported being on disability (51.06%, *n*=24), with only 21.28% (*n*=10) currently employed. Most participants reported an annual household income lower than $20,000 (67.79%, *n*=32).

The sample consists of newly diagnosed cancer survivors, as indicated by the fact that participants' average number of months since diagnosis at baseline was 1.11 ± 1.71. Most participants were diagnosed with head/neck cancer (87.23%, *n*=41). More than half of the participants were diagnosed with stage IV or metastatic cancer (51.11%, *n*=23). Most participants received some type of cancer treatment (93.48%, *n*=43), with many having multi-modal treatment (74.41%, *n*=32). Three participants died at some point during the course of the study (6.38%). Other details about participants' clinical characteristics may be found in Table 2.3.

Social functioning at baseline. Participants' main source of support primarily came from their familial relationships: spouse or partner (43.48%, *n*=20), child (30.43%, *n*=14), and other family member (13.04%, *n*=6); other sources included close friends,

religious groups, and health professionals (13.04%, *n*=6). Participants' scores on the SSQ, SCS and single-item social functioning measures are shown in Table 2.4. Given the nature of the skew, participants tended to report high levels of social support and low levels of social constraint.

Distress at baseline. Participants' continuous scores on the modified DT, HADS, and single-item distress measures are shown in Table 2.4; the data show a fairly normal distribution for each of the distress measures. In terms of the clinical significance of participants' distress scores, 63.83% (*n*=30) of the participants met the criterion for significant distress on the DT. On the HADS anxiety and depression subscales, 30.43% (*n*=14) and 14.89% (*n*=7) of the participants reported significant anxiety and depressive symptoms, respectively.

The three single-item measures of distress were significantly, positively correlated with each other (*r*s ranged from .64 to .89, all $p<.001$). Given this, the items were combined to create a composite "total" distress score. To maintain consistency across measures and to aid interpretation of findings, the individual distress scores were averaged together to create a total score that ranged from 0 to 9, with higher scores still indicative of greater distress. Coefficient alpha for the total distress score was 0.90. The average total distress score was 4.09 ± 2.97.

Longitudinal Analyses for Unconditional Multilevel Models

The panel plots in Figures 3.1, 3.2 and 3.3 show the within-person distribution for social support, social constraint, and distress, respectively. As shown, for each of these variables, there was relatively low variability throughout the daily assessment.

Table 3.1 displays the results from the unconditional growth model for social support and social constraint, and Table 3.2 shows the results for distress. On the first day of the daily assessment, participants' average level of social support was 5.69 (SE=.51; $p<.001$), their average level of social constraint was 2.21 (SE=.36; $p<.001$), and their average level of distress was 4.25 (SE=.44; $p<.001$), all on a 0 to 9 scale (see the Fixed Effects for "Intercept"). On average, participants' level of social support, social constraint, and distress did not significantly change over time (see the Fixed Effects for "Time"). However, a significant random effect of intercept was found for each of these variables, which indicates participants' starting level of social support, social constraint, and distress differed across people (see the Random Effects for "Intercept"). For each model, no significant individual variability in slopes was identified (see the Random Effects for "Time"). Finally, it was also found that an individual's level of distress on the first day was related to his or her change in distress over time (r=.06, p=.01). This means that distress increased more over time among individuals with higher distress during the first day. In contrast to distress, an individual's level of social support and social constraint on the first day was not associated with changes in his or her respective social support and social constraint over time ($r=.04$, $p=.16$ and $r=.03$, $p=.18$).

Longitudinal Analyses for Conditional Multilevel Models

For each conditional multilevel model, person-centered mean scores were used for each predictor and time was centered at the mid-point (i.e., day 15), given that the dependent variables did not change significantly over time in the unconditional models.

Average level of social support was unrelated to distress on a typical day ($p=.42$), and average level of distress was unrelated to social support on a typical day ($p=.36$); see

the Fixed Effects for "Social Support" and "Distress" in Table 3.3. In contrast, a significant, positive association was found between participants' average level of social constraint and distress on a typical day, with this effect observed in both directions (see the Fixed Effects for "Social Constraint" and "Distress" in Table 3.4). The model for distress suggest that for a person who is one unit higher in social constraint on average, her or his typical level of distress on the 0 to 9 scale increases by .83 units (SE=.16; $p<.001$). Similarly, the model for social constraint indicates that for a person who is one unit higher in average distress, her or his typical level of social constraint on that same scale increases by .53 units (SE=.10; $p<.001$). Social support and social constraint were unrelated to change in distress and distress was unrelated to change in social support and social constraint (*p*-values ranged from .21 to .94); see the Fixed Effects for "Social Support by Time" and "Distress by Time" in Table 3.3, and for "Social Constraint by Time" and "Distress by Time" in Table 3.4.

Table 3.1

Parameter Estimates for the Linear Growth Model of Social Functioning

Social Support					
				95% CI	
Fixed Effects (intercept, slopes)	Estimate (SE)	t(36)	*p*	Lower	Upper
Intercept (level at day 0)	5.69 (0.51)	11.15	.00	4.66	6.73
Time[1]	0.00 (0.01)	0.31	.78	-0.02	0.03
				95% CI	
Random Effects	Estimate (SE)	*z*	*p*	Lower	Upper
Level 2 (between-person)					
Intercept	8.98 (2.26)	3.98	.00	5.48	14.70
Time	-0.04 (0.04)	-1.20	.23	-0.12	0.03
Level 1 (within-person)					
Residual	2.50 (0.15)	16.74	.00	2.22	2.81
Autocorrelation	0.30 (0.04)	7.16	.00	0.21	0.38
Social Constraint					
				95% CI	
Fixed Effects (intercept, slopes)	Estimate (SE)	t(36)	*p*	Lower	Upper
Intercept (level at day 0)	2.21 (0.36)	6.13	.00	1.48	2.94
Time[1]	-0.01 (0.01)	-0.46	.65	-0.03	0.02
				95% CI	
Random Effects	Estimate (SE)	*z*	*p*	Lower	Upper
Level 2 (between-person)					
Intercept	4.12 (1.13)	3.63	.00	2.40	7.07
Time	-0.01 (0.02)	-0.34	.74	-0.05	0.04
Level 1 (within-person)					
Residual	3.47 (0.18)	19.16	.00	3.13	3.84
Autocorrelation	0.10 (0.04)	2.53	.01	0.02	0.18

Note. CI = confidence interval; [1] Time is coded where Day 1 = 0 … Day 30 = 29

Table 3.2

Parameter Estimates for the Linear Growth Model of Distress

Fixed Effects (intercept, slopes)	Estimate (SE)	t(36)	*p*	95% CI Lower	95% CI Upper
Intercept (level at day 0)	4.25 (0.44)	9.63	.00	3.36	5.15
Time[1]	0.13 (0.01)	0.93	.36	-0.01	0.04
Random Effects	**Estimate (SE)**	***z***	***p***	**95% CI Lower**	**95% CI Upper**
Level 2 (between-person)					
Intercept	6.61 (1.71)	3.88	.00	3.99	10.96
Time	-0.02 (0.04)	-0.49	.63	-0.10	0.06
Level 1 (within-person)					
Residual	1.98 (0.12)	15.92	.00	1.75	2.24
Autocorrelation	0.37 (0.04)	9.69	.00	0.29	0.44

Note. CI = confidence interval; [1] Time is coded where Day 1 = 0 … Day 30 = 29

Table 3.3

Parameter Estimates for the Linear Growth Model of Distress as a Function of Social Support and Vice Versa

Social Support → Distress

Fixed Effects (intercept, slopes)	Estimate (SE)	t(34)	*p*	95% CI Lower	95% CI Upper
Intercept (level at day 15)	5.15 (0.99)	5.20	.00	3.14	7.17
Time [1]	-0.00 (0.03)	-0.12	.90	-0.06	0.06
Social Support	-0.13 (0.15)	-0.82	.42	-0.44	0.19
Social Support by Time	0.00 (0.01)	0.62	.54	-0.01	0.01

Random Effects	Estimate (SE)	*z*	*p*	95% CI Lower	95% CI Upper
Level 2 (between-person)					
Intercept	6.93 (1.75)	3.97	.00	4.23	11.37
Time	0.04 (0.04)	1.01	.32	-0.04	0.12
Level 1 (within-person)					
Residual	1.98 (0.12)	15.93	.00	1.75	2.24
Autocorrelation	0.37 (0.04)	9.68	.00	0.29	0.44

Distress → Social Support

Fixed Effects (intercept, slopes)	Estimate (SE)	t(34)	*p*	95% CI Lower	95% CI Upper
Intercept (level at day 15)	6.47 (0.94)	6.87	.00	4.56	8.37
Time[1]	0.02 (0.02)	0.85	.40	-0.03	0.06
Distress	-0.17 (0.18)	-0.91	.36	-0.54	0.20
Distress by Time	-0.00 (0.01)	-0.84	.41	-0.01	0.01

Random Effects	Estimate (SE)	*z*	*p*	95% CI Lower	95% CI Upper
Level 2 (between-person)					
Intercept	8.19 (2.01)	4.07	.00	5.06	13.25
Time	-0.02 (0.03)	-0.55	.58	-0.08	0.05
Level 1 (within-person)					
Residual	2.50 (0.15)	14.91	.00	2.22	2.81
Autocorrelation	0.30 (0.04)	7.16	.00	0.21	0.38

Note. [1] Time is centered such that Day 15 = 0

Table 3.4

Parameter Estimates for the Linear Growth Model of Distress as a Function of Social Constraint and Vice Versa

Social Constraint→ Distress

Fixed Effects (intercept, slopes)	Estimate (SE)	t(34)	*p*	95% CI Lower	95% CI Upper
Intercept (level at day 15)	2.62 (.48)	5.40	.00	1.63	3.60
Time[1]	0.01 (.02)	0.55	.58	-0.03	0.05
Social Constraint	0.83 (.16)	5.10	.00	0.50	1.16
Social Constraint by Time	0.00 (.01)	0.08	.94	-0.01	0.01

Random Effects	Estimate (SE)	*z*	*p*	95% CI Lower	95% CI Upper
Level 2 (between-person)					
Intercept	3.88 (1.02)	3.79	.00	2.31	6.50
Time	0.03 (0.03)	1.05	.29	-0.03	0.09
Level 1 (within-person)					
Residual	1.98 (0.12)	15.91	.00	1.75	2.24
Autocorrelation	0.37 (0.04)	9.69	.00	0.29	0.44

Distress→ Social Constraint

Fixed Effects (intercept, slopes)	Estimate (SE)	t(34)	*p*	95% CI Lower	95% CI Upper
Intercept (level at day 15)	-0.17 (0.51)	-0.34	.74	-1.21	0.87
Time[1]	-0.02 (0.02)	-1.27	.16	-0.06	0.01
Distress	0.53 (0.10)	5.28	.00	0.32	0.74
Distress by Time	0.01 (0.00)	1.27	.21	-0.00	0.01

Random Effects	Estimate (SE)	*z*	*p*	95% CI Lower	95% CI Upper
Level 2 (between-person)					
Intercept	2.26 (0.60)	3.77	.00	1.34	3.80
Time	-0.01 (0.02)	-0.50	.62	-0.04	0.02
Level 1 (within-person)					
Residual	3.47 (0.18)	19.15	.00	3.13	3.85
Autocorrelation	0.11 (0.04)	2.57	.01	0.02	0.18

Note. [1] Time is centered such that Day 15 = 0

Figure 3.1
Panel Plots of the 30-Day Time Course of Social Support

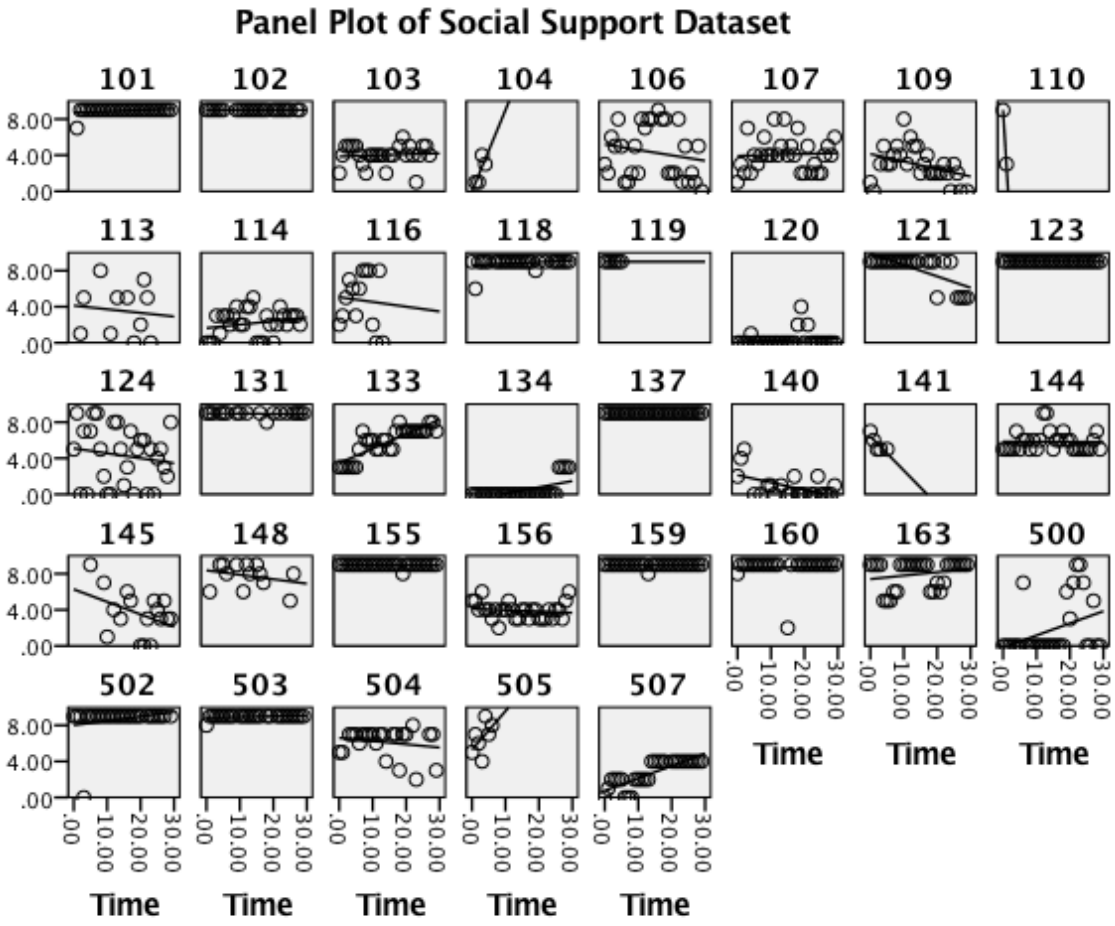


Figure 3.2

Panel Plots of the 30-Day Time Course of Social Constraint

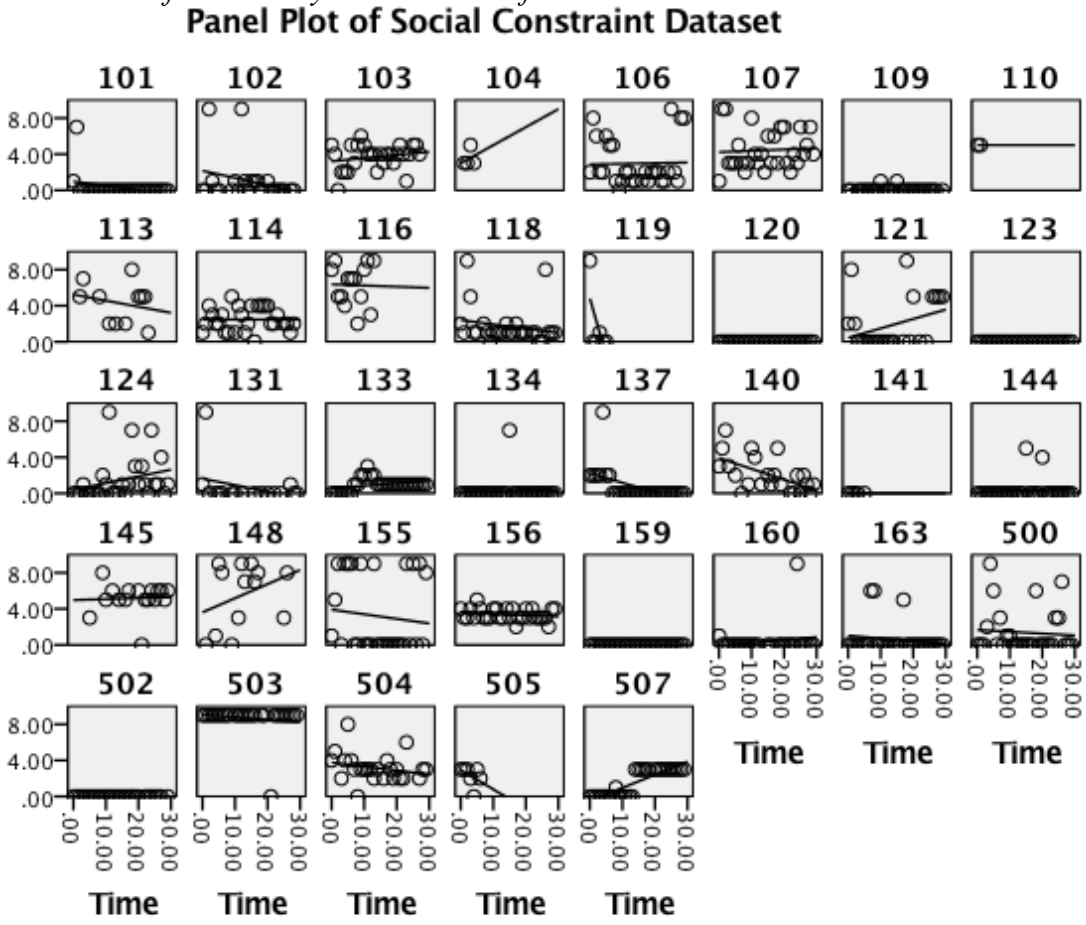
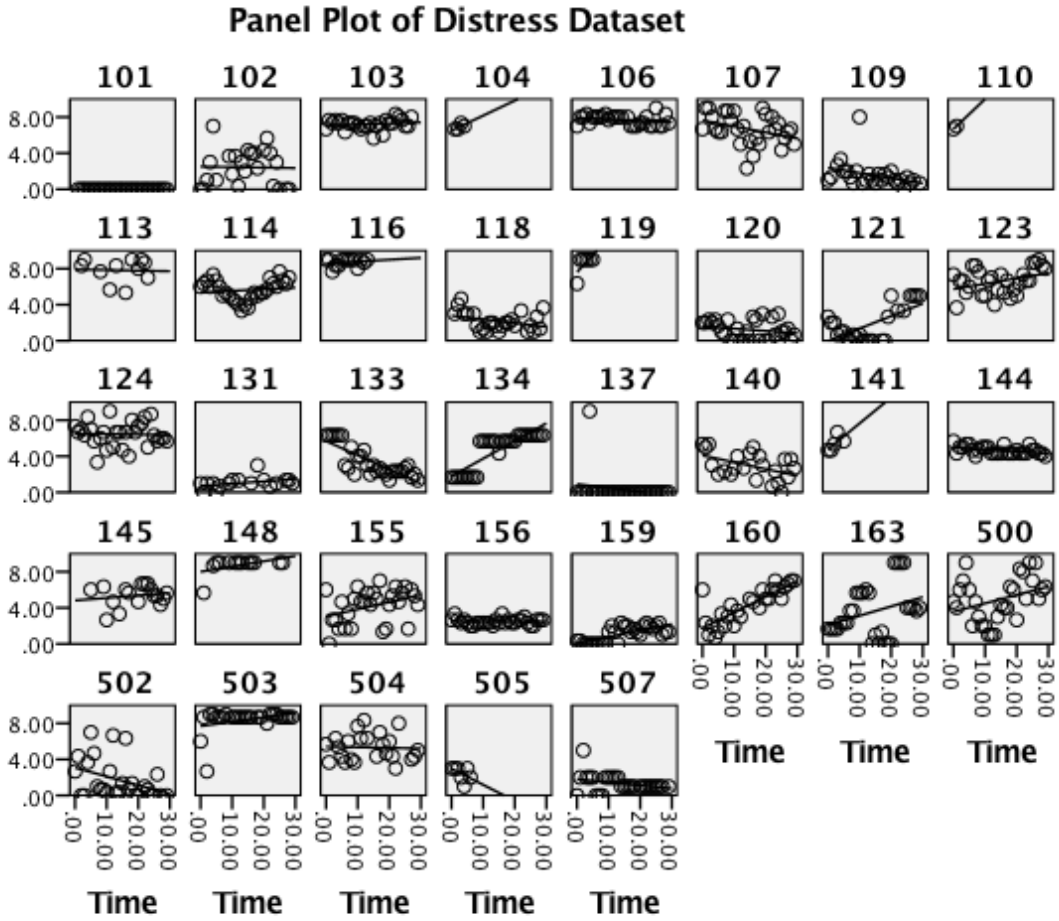


Figure 3.3

Panel Plots of the 30-Day Time Course of Distress



Chapter Four: Discussion

Drawing from a conceptual model where the sub-factors of QOL are inter-dependent, this study explored the nature and trajectory of social functioning and distress in recently diagnosed cancer survivors, and how these variables are related over time. In a complex fashion, the average baseline level of social functioning for this sample was both similar to, and different from, what is generally found in the cancer survivorship literature. The average level of social support (SSQ) in this sample of cervical and head/neck cancer survivors is similar to previous studies with breast cancer survivors (Osborne & Sinclair, 2004), advanced cancer survivors (Applebaum et al., 2014), and cancer survivors who smoked at time of diagnosis (Yang et al., 2013). The latter two comparison samples are noteworthy given the large proportion of participants with advanced disease, and the fact that all participants were smokers around the time of their diagnosis. As it pertains to social constraint (SCS), however, it would appear that participants reported higher levels than what was found in studies with gynecological and prostate cancer survivors (Zakowski et al., 2003; Zakowski, Ramati, Morton, Johnson, & Flanigan, 2004). Yet, no direct comparison of social constraint can be performed due to no previous studies having restricted their sample to participants with a recent cancer diagnosis or to only cervical or head/neck cancer survivors. Overall, it seems this sample's experience of social support is comparable to that found in other cancer samples while their experience of social constraint may be more pronounced.

As it pertains to their average baseline level of distress, participants reported similar levels of distress on the modified DT as what is found in prior studies with recently diagnosed head/neck cancer survivors (Buchmann, Conlee, Hunt, Agarwal, &

White, 2013; Lewis, Salins, Kadam, & Rao, 2013). In particular, there was a close alignment with a study of head/neck cancer survivors who were undergoing radiotherapy (Lewis et al., 2013). In contrast, when compared to studies of colon and prostate cancer survivors, participants in this study generally reported greater distress (Chambers et al., 2014; Patel et al., 2011). The finding of greater distress in the current sample is supported by a large study that evaluated level of distress by type of cancer diagnosis (Zabora et al., 2001). In Zabora and colleagues study (2001), head/neck cancer survivors were among the most distressed cancer survivors, which could be explained by the very high symptom burden and life disruption due to the site of the cancer and the grueling nature of its treatment. It should be noted, however, that in that same study gynecological cancer survivors (which includes cervical cancer survivors) had one of the lowest levels of distress. Thus, the relatively high level of distress observed here on the DT might be a result of the sample being primarily composed of head/neck as opposed to cervical cancer survivors. Of course, the DT was not the only measure of distress in this study. At baseline, participants' average anxiety and depression subscale scores (HADS) were higher than in a previous study with head/neck cancer survivors (Pandey, Devi, Thomas, Kumar, & Ramdas, 2007), though it should be noted that the other study had a smaller percent of survivors with advanced cancer. Similarly, as indexed by their average HADS total score, participants reported greater distress when compared to other studies with recently diagnosed cancer survivors (Patel et al., 2011; Stafford et al., 2014). In sum, this sample of recently diagnosed cervical and head/neck cancer survivors reported a baseline level of distress that is higher than cancer survivors in general, but perhaps what one would expect for cancer survivors with advanced disease and active treatment.

It was expected that two distinct aspects of social functioning (namely, social support and social constraint) would show different patterns of change during the 30-day daily assessment. Given that social support is often an intentional act, a reduction in social support might occur when survivors are believed to be doing better or have finished treatment and/or when supporters need to resume or reprioritize their own responsibilities. In contrast, because social constraint oftentimes happens unintentionally, supporters might routinely engage in socially constraining ways without full awareness, and in the absence of survivors calling direct attention to the behavior, this pattern of social interaction could continue indefinitely. Taken together, it was thought that as time passed, on average, participants would report less social support with no change in social constraint. Mixed support was found for the aforementioned hypotheses, as neither social support nor social constraint changed significantly over time. In general, previous longitudinal studies of cancer survivors' social functioning–studies that usually focus on the domain of social support–have found that social functioning tends to stay the same (Badr, Pasipanodya, & Laurenceau, 2013; Berg et al., 2008; Milbury, Badr, & Carmack, 2012; Zhou et al., 2010) or decline (De Leeuw et al., 2000; Salonen et al., 2012; Zakowski et al., 2004) over time. It should be noted, however, that nearly all prior longitudinal studies in this area rely on assessments that are spaced weeks, months, or even years apart, and it may be improper to compare and contrast study findings across arguably disparate methods. Worth mention then is that the results of this study also converge with those of two prior studies that used daily assessments in cancer survivors. Specifically, Berg and colleagues found that couples' level of collaborative coping (i.e., couples' active engagement in pooling resources, joint problem solving, and coping) did

not change over time and Badr and colleagues' study found cancer survivors' perceptions of social constraint (i.e., avoiding speaking to ones partner about ones thoughts and feelings related to cancer) also did not change over time (Badr et al., 2013; Berg et al., 2008). That said, it is important to highlight that social support and constraint in these studies were specific to married cancer survivors, and the period of observation was much shorter than what is used here (14 days) (Badr et al., 2013; Berg et al., 2008). Thus, the current findings give further support to the stability of social functioning over time and suggest this finding is not specific to married cancer survivors, who one might expect to have a more reliable source of support/constraint. In summary, while it is possible that the "null" results observed here are due to the 30-day window being too short a time period to see meaningful changes in social functioning, it is also possible that social support and constraint do not change significantly in the acute period after cancer diagnosis.

Similar to social functioning, the extent of participants' distress (3-item total score) did not change significantly over time. This finding was consistent across anxiety symptoms, depressive symptoms, and overall distress when evaluated independently using a series of unconditional multilevel models (data not shown). No significant changes were expected given that participants were recently diagnosed with cancer and/or in treatment, a period of time that is well established to be associated with at least modest distress levels (Andrykowski et al., 2008; Carlson, Waller, Groff, Giese-davis, & Bultz, 2013; Zabora et al., 2001). Thus, it was expected that while some days would be "good," others would be "bad," and overall, there would be no change over time. Other daily assessment studies with cancer survivors have similarly found that participants

individual and overall psychological functioning, does not change significantly over time (Berg et al., 2008; Sherliker & Steptoe, 2000). For example, the experience of negative emotion in prostate cancer survivors (who for the most part were recently diagnosed) did not change over a 14-day period (Berg et al., 2008), and recently diagnosed metastatic cancer survivors' reports of psychological well-being also did not change across four weeks of treatment (Sherliker & Steptoe, 2000). More traditional longitudinal studies have found conflicting results related to cancer survivors' long-term psychological functioning, such that at the present time, no singular pattern of change can be established across individuals (Carlson et al., 2013; de Graeff et al., 2000a; De Leeuw et al., 2000; Ferrandina et al., 2012; Hammerlid, Silander, Hornestam, & Sullivan, 2001; Mantegna et al., 2013; Neilson et al., 2010). As it pertains to head/neck and cervical cancer survivors specifically, some studies show an increase in distress (Neilson et al., 2010), others show a decrease in distress (De Leeuw et al., 2000), and still others show no change in distress (de Graeff et al., 2000a; Neilson et al., 2010). Overall, and akin to the results for social functioning, the "null" results for psychological functioning could be attributed to the study's methodology or to head/neck and cervical cancer survivors simply not experiencing any meaningful changes in distress so soon after cancer diagnosis.

In a QOL framework where the sub-factors are inter-dependent, it is expected that disruption (or improvement) in one QOL factor will negatively (or positively) affect other QOL factors (Bloom et al., 2007). Thus, a bidirectional, longitudinal relationship between social functioning and distress was hypothesized. In short, there was only modest support for this hypothesis. On the one hand, social constraint and distress did demonstrate a significant bidirectional relationship; no such relationship was observed for social support

and distress. On the other hand, there was no evidence (in either direction) of a longitudinal relationship between either social constraint or social support and distress. This means that while there was support for a connection between social constraint and distress on a typical day, there was no evidence that a change in distress from one day to the next was dependent upon a change in social constraint or vice versa. The lack of a longitudinal association is most easily explained by the fact that there was little to no change in these variables during the study period, which of course, makes change very difficult to predict.

It is important to consider these results in light of prior research. To date, more studies with cancer survivors have evaluated the longitudinal relationship between social support and distress (Alferi, Carver, Antoni, Weiss, & Durán, 2001; Badr, Laurenceau, Schart, Basen-Engquist, & Turk, 2010; Berg et al., 2008; Devine, Parker, Fouladi, & Cohen, 2003; Luszczynska et al., 2013; Roberts, Lepore, & Helgeson, 2006; Schroevers et al., 2003; Zhou et al., 2010) than social constraint and distress (Pasipanodya et al., 2012; Zakowski et al., 2004). Furthermore, of the available longitudinal studies, only three have investigated these relationships through daily assessment, and in all cases only unidirectional relationships were tested (e.g., social support predicts distress, Badr et al., 2010; Berg et al., 2008; Pasipanodya et al., 2012). Across studies, social support shows an inconsistent relationship with distress (Carpenter, Fowler, Maxwell, & Andersen, 2010; de Graeff et al., 2000a; De Leeuw et al., 2000; Naughton et al., 2002; Schmidt & Andrykowski, 2004; Smith et al., 2012) while social constraint is consistently, positively correlated with distress (Badr et al., 2013; Chambers et al., 2015; Cordova et al., 2001; Eton, Lepore, & Helgeson, 2001; Lepore & Helgeson, 1998; Nenova, Duhamel, Zemon,

Rini, & Redd, 2013; Schmidt & Andrykowski, 2004; Zakowski et al., 2003). In the few head-to-head comparisons, social constraint has shown a stronger relationship with distress than social support (Eton et al., 2001; Nenova et al., 2013; Schmidt & Andrykowski, 2004), possibly because its effect is universal. In other words, constraining behavior is detrimental to any and all cancer survivors, such that a lot of constraint is always "bad" and little to no constraint is always "good." Similarly, the experience of distress (because it is usually perceived as "bad") might incite social constraint from others. In contrast to social constraint, the modest role for social support in general could be because its receipt is psychologically beneficial for some while harmful for others (De Leeuw et al., 2000), essentially washing out its effect at the sample or population level. Even if that is the case, though, one might still expect a within-person association between distress and social support, as is sometimes found (Badr et al., 2010). In sum, a bidirectional positive relationship was found for social constraint and distress, and suggests that opportunities for cancer survivors to share their emotions and experiences may be important for distress management and likewise that the experience of distress may contribute to a "closed" or "constraining" social environment.

To our knowledge, no study published to date involves the same intensity and duration of naturalistic observations of social and/or psychological functioning after cancer diagnosis. Of the few other daily assessment studies in this area, they either include a smaller sample size than what was used here (Sherliker & Steptoe, 2000), involve a shorter period of observation, are not restrictive to those newly diagnosed with cancer (Badr et al., 2013; Berg et al., 2008), or do not evaluate the trajectory of change in the outcome (Badr et al., 2010; Fagundes, Berg, & Wiebe, 2012; Pasipanodya et al.,

2012). In addition, it is important to highlight that nearly half of participants in this study had stage IV disease, whereas other daily assessment studies only include survivors with less advanced disease (e.g., Belcher et al., 2011; Berg et al., 2008; Pasipanodya et al., 2012). Thus, this study attempts to tackle many of the methodological shortcomings of prior studies.

Despite its innovation and methodological rigor, this study is not without its limitations. First, the sample size is small, even for a data analytic approach that is designed to capitalize on the richness of intensive longitudinal data collection. That said, given the expectation of 30 consecutive days of assessment, the high symptom burden and arduous nature of cancer treatment, plus the stigma sometimes associated with smoking-related cancers, we anticipated a small sample size with a high degree of dropout. Nonetheless, the small sample size prohibited inclusion of covariates in the multivariate models, and it also prohibited the inclusion of both social support and social constraint as predictors of distress in the same model. Second, given that daily assessment studies require brevity for compliance, some of the key variables were measured with only one item, which is not ideal for complex psychosocial constructs. There is, of course, precedence for single item measures in daily assessment studies (e.g., Badr et al., 2010, 2013; Berg et al., 2008; Pasipanodya et al., 2012; Searles et al., 2002; Zhou et al., 2009), and more importantly, all of the single-item measures in this study were significantly associated with their respective multi-item measures at baseline, which suggest the single-item measures are targeting the same construct. Third, the null findings related to social support could be attributed to it being measured as too general as construct, as social support is known to be multidimensional (Dakof & Taylor, 1990;

Nausheen et al., 2009; Schroevers et al., 2010). Future studies should therefore include more specific dimensions of social support in an attempt to determine which, if any, dimensions change over time and are more strongly associated with distress (e.g., availability of support if needed, extent of social network). Fourth, the DT measure was modified from a 0-10 scale to 0-9 scale to avoid errors in data capture within the IVR system (i.e., a "10" is recognized/entered as a "1"). Due to this modification, the direct comparison between the DT results of this study and those of past and future studies that use the DT is somewhat limited. Fifth, participants who had the highest amounts of missing data during the daily assessment reported the highest anxiety levels at baseline, which could have implications for the generalizability of the results. However, given that restricted maximum likelihood estimator uses all available data to estimate any missing data, it is expected that the estimated data are a good proxy for the real values. Lastly, participants' demographic and clinical characteristics may limit the generalizability of study findings.

In summary, this study provides a greater understanding of two central aspects of QOL during the acute period of cancer diagnosis and treatment, namely social and psychological functioning. The results showed little change in social support, social constraint, and distress among recently diagnosed head/neck and cervical cancer survivors, results that may generalize to other cancer populations, in particular those with advanced disease and ensuing treatment. Of course, it might be the case that meaningful changes in social functioning and distress are in fact present among recently diagnosed cancer survivors, it is just that these changes are confined to a single day. If so, observation of change would require ecological momentary assessment, which was not

used here. It might also be the case that change in these constructs unfolds more slowly, over weeks or even months, in which case the more traditional approaches to longitudinal studies would be appropriate. For these reasons, it is not yet possible to "close the book" on changes in social functioning and distress after cancer diagnosis. Future studies are still needed to unpack the complexity of how cancer diagnosis might impact these QOL components. In addition to the results related to change over time (or the lack thereof), this study also showed that for a typical day, social constraint–but not social support–predicts distress and vice versa. These findings underscore the need to consider both positive and negative aspects of cancer survivors' social functioning in attempts to predict or explain their psychological functioning, at least as it pertains to the outcome of distress. Furthermore, these findings support existing theories, which purport that social functioning is multidimensional and its sub-components differentially impact distress. In conclusion, this study further highlights the importance of social functioning and distress after cancer diagnosis, and raises the possibility that improvements in one QOL domain may be achieved through improvements in another, related QOL domain.

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PROFESSIONAL POSITIONS

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PUBLICATIONS

Rivera-Rivera, J.N., Aubrey, E., Puleo, G., Burris, J.L. (In progress). The Independent Association Between SES and Health-Related Quality of Life in Cervical Cancer Survivors: A US Population-Based Study.

Rivera, J.N., Rodríguez, S., Varas, N., & Pacheco, R.Y. (2013). The Role of Social Support on Health-Related Practices of HIV-Discordant Heterosexual Couples. *Revista Puertorriqueña de Psicología,* 24 (2).

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