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MEASURES OF CANCER-RELATED LONELINESS AND NEGATIVE SOCIAL EXPECTATIONS: DEVELOPMENT AND PRELIMINARY VALIDATION

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TABLE OF CONTENTS

Page

ABSTRACT

Adams, Rebecca N. Ph.D., Purdue University, August 2016. Measures of Cancer-related Loneliness and Negative Social Expectations: Development and Preliminary Validation. Major Professor: Catherine E. Mosher.

Loneliness is a known risk factor for poor mental and physical health outcomes in the general population, and preliminary research suggests that loneliness is linked to poorer health in cancer patients as well. Various aspects of the cancer experience (e.g., heightened existential concerns) lend themselves to making patients feel alone and misunderstood. Furthermore, loneliness theory suggests that negative social expectations, which may specifically relate to the cancer experience, precipitate and sustain loneliness. Thus, loneliness interventions in cancer should be tailored to address illness-related social conditions and negative social expectations. Prior to the development of loneliness interventions for cancer populations, cancer-specific tools are needed to assess: (1) loneliness attributed to cancer (i.e., cancer-related loneliness), and (2) negative social expectations related to cancer. In the current project I developed measures of cancer-related loneliness and cancer-related negative social expectations for use in future theory-based loneliness research. A mixed-methods study design was employed. First, I developed items for the measure of cancer-related loneliness (i.e., the Cancer Loneliness Scale) based on theory, prior research, and expert feedback. Second, I conducted a clinic-based qualitative study (*n*=15) to: (1) obtain cancer patient feedback on the Cancer Loneliness Scale items, and (2) inform development of the item pool for the measure of negative social expectations (i.e., the Cancer-related Negative Social Expectations Scale). Interviews were audiotaped, transcribed verbatim, and then transferred to Atlas.ti for analysis. Content analysis was used to analyze data regarding patient feedback and theoretical thematic analysis was used to analyze data regarding negative social expectations. Overall, patients said they liked the Cancer Loneliness Scale and no changes were made to the items based on patient feedback. Based on results, I also created five content domains of negative social expectations that were represented in the item pool for the Cancer-related Negative Social Expectations Scale. Third, I conducted a telephone and mail-based quantitative study (*n*=186) to assess psychometric properties of the two new measures. Dimensionality was determined using confirmatory factor analysis. Reliability was assessed by examining internal consistency coefficients and construct validity was assessed by examining theoretical relationships between the Cancer Loneliness Scale, the Cancer-related Negative Social Expectations Scale, and existing reliable and valid measures of health and social well-being. The final products of the project included a 7-item unidimensional Cancer Loneliness Scale and 5-item unidimensional Cancer-related Negative Social Expectations Scale. Excellent evidence for reliability and validity was found for both measures. The resulting measures have both clinical and research utility.

INTRODUCTION

Loneliness is a known risk factor for poor mental and physical health outcomes in the general population, and preliminary research suggests that loneliness is linked to poorer health in cancer patients as well (Cacioppo & Hawkley, 2009; Cacioppo et al., 2006; Hawkley & Cacioppo, 2003; Jaremka, Andridge, et al., 2014; Jaremka, Fagundes, Glaser, et al., 2013). Various aspects of the cancer experience lend themselves to making patients feel alone and misunderstood. For example, many cancer patients have heightened existential concerns following a cancer diagnosis but feel that family members do not share these concerns (Lee, 2008; Rosedale, 2009; Sand, Strang, & Milberg, 2008). In addition, some patients feel constrained in discussing cancer-related concerns with others (Lepore & Revenson, 2007). Furthermore, loneliness theory suggests that negative social expectations may precipitate and sustain loneliness (Cacioppo & Hawkley, 2009). Negative social expectations may specifically relate to the cancer experience; for instance, patients may expect a high level of support and sympathy from friends and family following a cancer diagnosis and feel disappointed when these expectations are not met. In sum, theory and research suggest that loneliness may have unique precipitants in cancer patients, as many of the social experiences linked to their loneliness may be cancer-related. Thus, tailoring loneliness interventions to address cancer-related experiences may be indicated. However, the loneliness literature with cancer patients is limited and, thus, further research is needed before we can proceed with interventions to reduce loneliness in this population. Current gaps in the literature include: (1) assessment of the degree to which patients attribute their loneliness to cancer-related experiences; and (2) identification and assessment of cancer-related negative social expectations theorized to sustain loneliness (Cacioppo & Hawkley, 2009). This study begins to address these gaps by developing two cancer-specific tools for use in research to assess: (1) loneliness attributed to cancer (i.e., cancer-related loneliness); and (2) negative social expectations related to cancer that may precipitate and sustain loneliness.

First, I will define loneliness, discuss its relationship to poorer mental and physical health outcomes, and summarize existing research on interventions to reduce loneliness. Next, I will discuss the current state of the loneliness literature with cancer patients, including prevalence, predictors, relationships to psychological and somatic symptoms, and interventions. Following this review, I will present my study aims and hypotheses, study methods, results, and discussion.

Loneliness

Feeling socially connected is a critical aspect of well-being; in the absence of social connection, we experience loneliness. Relationship quality has been found to be more predictive of loneliness than relationship quantity (Pinquart & Sorensen, 2001). Additionally, some evidence suggests that lonely people spend the same amount of time alone or engaging in activities with others as non-lonely people (Cacioppo et al., 2000). Although some lonely people may have limited social interactions, loneliness is defined by the *perception* of social isolation and is characterized by dissatisfaction with the *quality* of relationships (Peplau & Perlman, 1982).

Evolutionary theories of loneliness posit that human interaction is a core human motivation (Baumeister & Leary, 1995). It has been suggested that feelings of loneliness might have evolved as a signal to human beings that they need to become more socially connected (Cacioppo, Cacioppo, & Boomsma, 2014; Cacioppo et al., 2006). According to these theories, social connection is evolutionarily adaptive, with the genetic contribution to loneliness estimated to be 50% (Boomsma, Willemsen, Dolan, Hawkley, & Cacioppo, 2005; Distel et al., 2010; Goossens, 2012; McGuire & Clifford, 2000). The dissolution of social relationships leads to social pain, which shares many neural mechanisms with the brain's response to physical pain (Eisenberger & Lieberman, 2004, 2005). Thus, although it has negative implications for long-term health (Cacioppo, Hawkley, & Thisted, 2010; Hawkley & Cacioppo, 2003), in the short-term loneliness may serve as an adaptive reminder to increase social connection.

Loneliness is a phenotype characterized by a number of cognitive, emotional, and behavioral symptoms (Cacioppo & Cacioppo, 2012). Evidence suggests that lonely individuals have maladaptive hypervigilance for social threat (Cacioppo, Norris, Decety, Monteleone, & Nusbaum, 2009; Duck, Pond, & Leatham, 1994; Kanai et al., 2012). For example, lonely individuals show greater visual attention to negative social stimuli than non-lonely individuals (Cacioppo, Norris, et al., 2009). Experimental manipulation of loneliness via hypnosis showed that loneliness can increase shyness, anxiety, and fear of negative evaluation and decrease positive mood and social skills (Cacioppo et al., 2006). Further, loneliness may be "contagious" within social networks; one study utilizing continuous surveillance data found that interactions with lonely individuals predicted greater feelings of loneliness following interactions (Cacioppo, Fowler, & Christakis, 2009). Cacioppo and Hawkley (2009) propose that cognitive features associated with loneliness (e.g., hypervigilance for social threat) fit into a regulatory loop that sustains loneliness and increases factors, such as poor sleep quality and hypothalamic-pituitary-adrenocortical [HPA] axis activation, which lead to poor health outcomes. According to this theory, lonely individuals have more negative expectations of others and are viewed more negatively by others. Negative expectations invite more negative interactions that, in turn, sustain perceptions of social isolation and hypervigilance to social threat. The persistence of the loop may be affected by social conditions (i.e., whether or not others in the environment choose to form connections with the lonely individual).

Although loneliness has been described as multi-dimensional (i.e., chronic and situational loneliness have been distinguished; de Jong-Gierveld & Raadschelders, 1982), little research has examined the differential health impact of chronic versus situational loneliness. Shiovitz-Ezra and Ayalon (2010) found that, although both situational and chronic loneliness predicted increased risk for mortality, individuals who were chronically lonely had greater mortality risk.

Although the current prevalence of loneliness in the United States is unknown, Hawthorne (2008) reported that 9% of Australian adults reported some social isolation, and 7% reported more frequent isolation. Recent studies have found that loneliness is most prevalent in older adults and young adults or adolescents (Pinquart & Sorensen, 2001; Victor & Yang, 2012). Hence, much of the literature on loneliness focuses on these age groups. Consistent predictors of loneliness include marital status, income, and health status, such that unmarried individuals, those with lower incomes, and those with disabilities and functional limitations are more lonely (Cohen-Mansfield, Shmotkin, & Goldberg, 2009; Hawkley et al., 2008; Hawthorne, 2008; Pinquart & Sorensen, 2001; Rokach, Lechcier-Kimel, & Safarov, 2006; Savikko, Routasalo, Tilvis, Strandberg, & Pitkälä, 2005; Theeke, 2009).

Loneliness and Mental Health

In addition to identifying demographic predictors of loneliness, researchers have consistently linked loneliness to poorer mental health (Heinrich & Gullone, 2006). Loneliness has been found to be related to greater general psychological distress (Paul, Ayis, & Ebrahim, 2006), poorer quality of life (Steptoe & Marmot, 2003), lower self-esteem and well-being (Cacioppo et al., 2006; Riggio, Watring, & Throckmorton, 1993), and greater anxiety, including social anxiety (Anderson & Harvey, 1988; Cacioppo et al., 2006). The relationship between loneliness and depression is the most well documented; a higher level of loneliness has been linked to greater depressive symptoms in adolescents (Mahon, Yarcheski, Yarcheski, Cannella, & Hanks, 2006), college students (Swami et al., 2007; Wei, Russell, & Zakalik, 2005), and older adults (Adams, Sanders, & Auth, 2004; Alpass & Neville, 2003; Golden et al., 2009; Luanaigh & Lawlor, 2008). Five- and ten-year longitudinal studies have shown that higher levels of loneliness predict increased depressive symptoms in older adults (Cacioppo et al., 2010; Heikkinen & Kauppinen, 2004). Additionally, greater loneliness appears to be related to thoughts of suicide (Stravynski & Boyer, 2001). Therefore, interventions to reduce loneliness may result in meaningful reductions in depressive symptomatology (VanderWeele, Hawkley, Thisted, & Cacioppo, 2011).

Loneliness and Physical Health

Greater loneliness has also been associated with poorer physical health (Hawkley & Cacioppo, 2003). In particular, having a higher level of loneliness is a risk factor for cardiovascular problems (Caspi, Harrington, Moffitt, Milne, & Poulton, 2006). For example, in a 20-year follow-up study of women, being lonely during the day predicted myocardial infarction or coronary death (Eaker, Pinsky, & Castelli, 1992). Another study reported that, at 14-year follow-up, greater loneliness predicted cardiovascular mortality in men (Olsen, Olsen, Gunner-Svensson, & Waldstrøm, 1991). Thurston and Kubzansky (2009), on the other hand, found that greater loneliness predicted coronary heart disease incidence in women, but not men. Increased loneliness also predicted higher total peripheral resistance, which may contribute to hypertension, in young adults (Hawkley, Burleson, Berntson, & Cacioppo, 2003). Furthermore, Caspi et al. (2006) found that socially isolated children had a greater number of risk factors for poor health (e.g., overweight, high blood pressure, high cholesterol) at 20-year follow-up than children who had not been socially isolated at baseline.

Greater loneliness has also been linked to poorer cognitive functioning (Cacioppo & Hawkley, 2009). Over 5- and 10-year periods, loneliness was related to greater decline in cognitive ability and performance and poorer executive functioning (Cacioppo & Hawkley, 2009; Tilvis et al., 2004; Wilson et al., 2007). Additionally, the risk of developing late-life Alzheimer’s disease in older adults is more than double for lonely individuals (Wilson et al., 2007).

Why is Loneliness Related to Health Outcomes?

Although it is clear that greater loneliness is related to poorer health outcomes, the explanation for this relationship is unknown. Hawkley and Cacioppo (2010) have proposed several potential mechanisms to explain this relationship including: neuroendocrine effects, genetic effects, immune functioning, sleep disturbance, and engagement in health behaviors.

Some research suggests that the potential mechanisms of neuroendocrine, genetic, and immune functioning might explain relationships between loneliness and poor health outcomes. For example, higher loneliness is related to increased blood pressure (Hawkley, Thisted, Masi, & Cacioppo, 2010) and higher levels of epinephrine (Hawkley, Masi, Berry, & Cacioppo, 2006) which, when elevated, have detrimental effects on health. Additionally, levels of the stress hormone cortisol are also heightened in lonely individuals (Cacioppo et al., 2000; Doane & Adam, 2010; Kiecolt-Glaser et al., 1984; Pressman et al., 2005; Steptoe, Owen, Kunz-Ebrecht, & Brydon, 2004), leading to greater activation of the HPA axis. In a review of stress system disorders, Chrousos and Gold (1992) discussed the many medical conditions associated with increased HPA axis activity, including hypertension and other chronic diseases. Increased levels of cortisol in lonely people may also desensitize the glucocorticoid receptor pathway, making cells insensitive to anti-inflammatory effects. Therefore, differences in the transcription of glucocorticoid response genes and increased activity of pro-inflammatory transcription control pathways between lonely and non-lonely individuals may help explain the impact of loneliness on health (Cole et al., 2007). Furthermore, evidence suggests that greater loneliness is related to poorer immune functioning (e.g., lower active killer cell activity, poorer T-lymphocyte response, decreased antibody response) (Glaser, Kiecolt-Glaser, Speicher, & Holliday, 1985; Kiecolt-Glaser et al., 1984).

The potential mediating role of sleep disturbance in the relationship between loneliness and health has also garnered some attention. Lonely college students and older adults report poorer sleep, experience poorer sleep efficiency, and spend more time awake than their non-lonely peers (Cacioppo, Hawkley, Berntson, et al., 2002; Cacioppo, Hawkley, Crawford, et al., 2002). Loneliness was also related to sleep disturbance in early and middle adolescents (Mahon, 1994). Furthermore, in a large study of adolescents and adults in seven European countries, Ohayon (2005) found that those less satisfied with their social network experienced more nonrestorative sleep than those more satisfied with their social network. Decreased quality and quantity of sleep could make lonely individuals less resistant to health threats.

The mediating role of health behaviors, such as smoking, diet, exercise, and alcohol and drug use, in the relationship between loneliness and health has been less clear. Cacioppo, Hawkley, Crawford, et al. (2002) found no difference in alcohol consumption, drug use, number of cigarettes smoked, or exercise duration between groups of lonely and non-lonely undergraduate students and adults (Cacioppo, Hawkley, Crawford, et al., 2002). However, other studies have suggested that lonely individuals engage in less health-promoting behaviors. For example, Theeke (2010) found that chronically lonely older adults used more tobacco and exercised less than those who were not chronically lonely. Other studies found that lonely people were more likely to smoke, be overweight, and have higher body mass indexes (BMIs) than non-lonely people (DeWall & Pond, 2011; Lauder, Mummery, Jones, & Caperchione, 2006; Shankar, McMunn, Banks, & Steptoe, 2011). Additionally, loneliness predicted reduced odds of engagement in physical activity in adult samples (Reed, Crespo, Harvey, & Andersen, 2011; Shankar et al., 2011). Greater loneliness also has been linked to the full spectrum of eating disorders (Levine, 2012), and lonely student dieters ate more than non-lonely student dieters when offered free food (Rotenberg & Flood, 1999).

Interventions for Loneliness

Given the poor health outcomes associated with loneliness, a number of interventions have been developed to reduce it (Cattan, White, Bond, & Learmouth, 2005; Findlay, 2003; Masi, Chen, Hawkley, & Cacioppo, 2010). Loneliness interventions have targeted various populations, including children and adolescents (e.g., Allen-Kosal, 2008; Bauminger, 2007; Stewart, Craig, MacPherson, & Alexander, 2001), college students (e.g., Conoley & Garber, 1985; Seepersad, 2005) older adults (e.g., Banks, Willoughby, & Banks, 2008; McAuley et al., 2000; Ollonqvist et al., 2008), individuals with severe mental illness (e.g., Bauminger, 2007; Kolko, Loar, & Sturnick, 1990; Petryshen, Hawkins, & Fronchak, 2001), and individuals with medical conditions (e.g., Christian & D'Auria, 2006; Cox, Green, Hobart, Jang, & Seo, 2007; Fukui, Koike, Ooba, & Uchitomi, 2003; Heckman et al., 2006), with the majority of studies focusing on older adults.

Masi et al. (2010) published a systematic review and meta-analysis of loneliness reduction interventions. Their meta-analytic results indicated that studies using a randomized comparison design had smaller effect sizes than studies using a pre-post or non-randomized comparison design. Among studies using a randomized comparison trial design, a wide range of effect sizes was found, with differences in intervention strategies partially accounting for these results. The authors reported that four primary intervention strategies have been used to reduce loneliness: reducing maladaptive social cognitions, improving social skills, enhancing social support, and increasing opportunities for social contact. Control groups varied across studies and included usual care, wait-list control, and educational control groups. Among studies using a randomized comparison design, interventions that addressed maladaptive social cognitions were most successful. In fact, the mean effect size for these interventions was medium (i.e., *d* = -.59), whereas the mean effect sizes for each of the other three strategies were small (i.e., *ds* = .02 to -.16). No significant differences were found between the effect sizes of the other three intervention strategies, and the only other strategy found to have a significant effect on loneliness was enhanced social support (*d* = -.16). Overall, these findings are consistent with loneliness theory which emphasizes the role of social cognitions in loneliness (Cacioppo et al., 2014; Cacioppo & Hawkley, 2009; Cacioppo et al., 2006).

Loneliness in Cancer

About 40% of all men and women will be diagnosed with cancer at some point during their lifetime, with approximately 66% surviving 5 years post-diagnosis (SEER, 2013). Unfortunately, cancer patients experience high rates of psychological and somatic symptoms, existential concerns, and social challenges during and after treatment (Brintzenhofe-Szoc, Levin, Li, Kissane, & Zabora, 2009; Kroenke, Johns, Theobald, Wu, & Tu, 2013; Pirl, 2004). In addition, many aspects of the cancer experience lend themselves to making patients feel alone and misunderstood.

A vulnerability-stress model (Gibb & Coles, 2005) may be a useful framework for understanding loneliness in cancer patients. Genetically-predisposed dysfunctional attitudes or expectations regarding social relationships would constitute the vulnerability and, when patients with such attitudes encounter cancer (i.e., the stressor), they may be more likely to develop loneliness than patients without such attitudes. Among cancer patients, the maladaptive social cognitions and social experiences characteristic of loneliness may specifically relate to aspects of the cancer experience. For example, patients may expect a high level of support and sympathy from friends and family following a cancer diagnosis; yet many may feel disappointed or alienated when members of their social network do not provide the support that they anticipated.

Although theory suggests that cancer may exacerbate loneliness in some individuals (Gibb & Coles, 2005), the empirical literature on loneliness in cancer patients is limited. Significant variability in cancer patients’ loneliness levels exists between studies, with some studies suggesting that cancer patients do not experience greater levels of loneliness than other populations (i.e., healthy peers, individuals with other chronic conditions) (Pendley, Dahlquist, & Dreyer, 1997; Penninx et al., 1999; Rijken, Komproe, Ros, Winnubst, & Heesch, 1995), and other studies suggesting that their loneliness levels are greater than those found in the general population (Fox, Harper, Hyner, & Lyle, 1994; Sahin & Tan, 2012). Loneliness scores on the UCLA Loneliness Scale have sometimes been categorized as low, moderate, or high (possible range = 20 to 80). Average loneliness levels in cancer patients on the UCLA Loneliness Scale have varied from low (scores less than 28) to high (scores greater than 46) between studies, with the majority of studies reporting moderate levels of loneliness on average (Fogel, Albert, Schnabel, Ditkoff, & Neugut, 2002; Fox et al., 1994; Friedman, Florian, & Zernitsky-Shurka, 1989; Jaremka, Fagundes, Peng, et al., 2013; Pehlivan, Ovayolu, Ovayolu, Sevinc, & Camci, 2012; Perry, 1990; Sahin & Tan, 2012; Sevil, Ertem, Kavlak, & Coban, 2006; Yildirim & Kocabiyik, 2010). Indeed, a recent meta-analysis reported that cancer patients experience a moderate level of loneliness on average (Deckx, van den Akker, & Buntinx, 2014).

Demographic and Medical Correlates of Loneliness in Cancer

Limited research has examined demographic and medical correlates of loneliness in cancer patients. A meta-analytic review of loneliness correlates in cancer patients reported that loneliness is more common in unmarried patients and tends to increase as more time elapses since the cancer diagnosis (Deckx et al., 2014). The authors reported no relationship between loneliness and cancer type or the mean age of the study sample. In primary studies of cancer patients, the majority of studies have found no relationship between loneliness and gender, educational level, age, disease stage, or cancer type (Avci & Kumcagiz, 2011; Friedman et al., 1989; Jaremka, Fagundes, Glaser, et al., 2013; Pehlivan et al., 2012; Perry, 1990; Sevil et al., 2006; Yildirim & Kocabiyik, 2010). Relationships between loneliness and marital status and time since diagnosis have been mixed, with some studies finding that individuals who are married and more recently diagnosed are less lonely than those who are unmarried and less recently diagnosed and other studies finding no significant relationships (Avci & Kumcagiz, 2011; Friedman et al., 1989; Pehlivan et al., 2012; Perry, 1990; Yildirim & Kocabiyik, 2010).

Social Correlates of Loneliness in Cancer

Theory and limited research suggest that social support and social constraints are associated loneliness (Deckx et al., 2014; Lepore, 2001; Mosher et al., 2012). Social support is a positive social variable indicating the actual or perceived amount of emotional or practical support provided by others (Helgeson & Cohen, 1996). On the other hand, social constraints occur when an individual feels compelled to modify the expression of stressor-related thoughts or feelings due to social conditions (i.e., others' actual or perceived behaviors) (Lepore & Revenson, 2007). According to social cognitive processing theory (Lepore, 2001), a socially constraining environment impedes adjustment by preventing successful cognitive and emotional processing of new information regarding a stressor (e.g., cancer). Conversely, a supportive social environment facilitates the processing of stressor-related information, which in turn promotes adjustment. Cancer patients often process their cancer-related thoughts and feelings by talking about their concerns with important others; thus, patients' psychological adjustment may be affected when they feel unable to share their concerns (Davison, Pennebaker, & Dickerson, 2000; Gotcher, 1993; Lepore, 2001). Consistent with this theoretical perspective (Lepore, 2001), higher levels of social constraints were associated with greater loneliness among cancer patients in one study (Mosher et al., 2012), whereas higher levels of social support were associated with less loneliness in several studies with this population (Mosher et al., 2012; Sahin & Tan, 2012; Yildirim &

Kocabiyik, 2010). Furthermore, in one qualitative study, head and neck cancer patients reported that more contact with other cancer patients reduced their feelings of loneliness (Egestad, 2013).

Loneliness and Health Outcomes in Cancer

Loneliness has been associated with a number of psychological and physical health outcomes in cancer patients. Regarding psychological health outcomes, loneliness has been positively related to distress and hopelessness and negatively related to quality of life, self-esteem, and optimism in medically diverse samples of cancer patients and survivors (Jaremka, Fagundes, Glaser, et al., 2013; Mosher et al., 2012; Pace & Stables, 1997; Pehlivan et al., 2012; Rijken et al., 1995). In a 1-year study of breast cancer patients, greater loneliness predicted increased depressive symptoms longitudinally, whereas depression did not predict changes in loneliness over time (Jaremka, Andridge, et al., 2014). Regarding physical health outcomes, loneliness has been positively associated with fatigue and pain and negatively associated with sleep quality and self-reported physical health in recently diagnosed and long-term cancer survivors (Ferrell, Dow, & Grant, 1995; Jaremka, Fagundes, Glaser, et al., 2013; Rijken et al., 1995). In a study of breast cancer patients, greater loneliness predicted increases in fatigue and pain over time, whereas these symptoms did not predict changes in loneliness (Jaremka, Andridge, et al., 2014). In two studies, loneliness was associated with greater incidence of cancer and all-cause mortality (Drageset, Eide, Kirkevold, & Ranhoff, 2013; Fox et al., 1994), and one recent study found that expression profiles for loneliness-related genes predicted survival time in cancer patients, such that patients with high-risk loneliness profiles had a shorter survival time on average than patients with a low-risk loneliness profile (You, Yeh, & Su, 2014). Furthermore, studies have found links between higher levels of loneliness and poorer immune functioning in breast cancer patients (Jaremka, Fagundes, Peng, et al., 2013; Nausheen et al., 2010). In contrast, another study found no relationship between loneliness and disease markers in breast cancer patients (Giraldi, Rodani, Cartei, & Grassi, 1997).

Cancer-related Experiences Associated with Loneliness

Qualitative researchers have begun to document aspects of the cancer experience that patients perceive as precipitants of loneliness. First, many patients report feeling alone in a number of illness-related situations (e.g., during diagnosis, during appointments, while making important medical decisions) (Friedman et al., 1989; Madsen, Holm, & Riis, 2007). Second, some patients report that their psychological and somatic symptoms have caused them to become more dependent on others; yet, over time, they receive less emotional support and have fewer conversations with family members concerning their illness, which makes them feel devalued (Sand et al., 2008). Further, many patients report heightened existential concerns (e.g., fear of death) during and after cancer treatment and feel that those around them do not share their new awareness of mortality or understand their concerns (Rosedale, 2009; Sand et al., 2008). Additionally, although patients typically report an intensified desire to connect with others, many also report withholding fears from others in order to protect them, which hinders social connection (Rosedale, 2009). Thus, qualitative work provides some useful insights into the experiences that contribute to feelings of isolation in cancer patients.

Theory and research point to other social conditions surrounding cancer that might contribute to loneliness as well. For example, emotional processing of stressful information with others is hypothesized to facilitate patients' adjustment (Park, 2010), yet many patients report that their family members and friends avoid discussing the cancer or find conversations regarding cancer to be difficult (Lepore & Revenson, 2007). Some family members and friends may feel uncomfortable around patients and avoid them altogether (Lepore & Revenson, 2007). Others may avoid conversations about illness and death because they feel it is in the best interest of the patient (Kuijer et al., 2000; Langer, Brown, & Syrjala, 2009), though patients tend to report that they want to talk about their illness (Davison et al., 2000). Moreover, some cancer patients report experiencing stigma (i.e., exclusion, blame, rejection, and devaluation based on a judgment concerning their illness) (Butts Stahly, 1989; Cataldo, Slaughter, Jahan, Pongquan, & Hwang, 2011; Muzzin, Anderson, Figueredo, & Gudelis, 1994). In particular, patients whose cancer is perceived to be caused by their own behaviors (i.e., lung cancer and to a lesser extent cervical and bowel cancer) tend to experience the most stigma (Lebel & Devins, 2008; Marlow, Waller, & Wardle, 2010). Additionally, some patients report stigma following physical changes that often accompany cancer and its treatment, such as hair loss (Rosman, 2004). Given these circumstances, it is not surprising that many cancer patients report feeling lonely and misunderstood.

Interventions for Loneliness in Cancer Patients

Despite evidence presented that (1) loneliness is an important quality-of-life concern for cancer patients; (2) greater loneliness is related to poorer mental and physical health in cancer patients and the general population; and (3) some loneliness interventions are efficacious in the general population, literature regarding loneliness interventions for cancer patients is sparse. Five studies with cancer patients that examined loneliness as an intervention outcome did not specifically tailor the intervention to reduce loneliness (Cleary & Stanton, 2015; Coleman et al., 2005; De Vries et al., 1997; Marcus, Blazek-O'Neill, & Kopar, 2013; Samarel, Tulman, & Fawcett, 2002). Rather, loneliness was one of many outcomes examined, such as distress, relational outcomes, and somatic symptoms. These studies employed standard psychotherapy, telephone-based social support, psychoeducation, and Reiki (a type of spiritual healing) to improve patient outcomes. Three of these interventions led to decreased loneliness at certain time points (Cleary & Stanton, 2015; Marcus et al., 2013; Samarel et al., 2002). To my knowledge, only one published trial specifically tested an intervention to reduce loneliness and increase social support in cancer patients (Fukui et al., 2003). Japanese women with breast cancer participated in this 6-week group-based intervention focused on health education, coping skills training, stress management, and psychological support. At the end of the 6-week intervention, women assigned to the intervention reported significantly less loneliness and greater satisfaction with confidants than the wait-list control group, though differences were modest. Taken together, preliminary evidence indicates that interventions might reduce loneliness in a cancer population, but more work is needed to determine whether other intervention strategies may lead to greater decreases in loneliness. For example, no published intervention trials with cancer patients have addressed maladaptive social cognitions linked to loneliness, which was found to be the most successful strategy for loneliness reduction in the general population (Masi et al., 2010). Further intervention studies are needed to determine the most effective strategies for reducing loneliness in cancer patients.

Present Study

Cancer patients may experience loneliness specifically related to their cancer experience. For example, patients' loneliness-related cognitions may refer to the cancer experience (e.g., unrealistic expectations regarding others' level of understanding and support during their illness). Further, different social factors may be associated with loneliness in cancer patients relative to non-cancer populations. For instance, although the size of one's social network and the amount of social contact is not associated with loneliness in the general population (Peplau & Perlman, 1982; Russell, 1996), cancer patients have reported that more contact with other patients led them to feel less lonely (Egestad, 2013). Thus, interactions with other patients may be an important factor that is unique to loneliness in cancer populations. Loneliness interventions in cancer should be tailored to address illness-related social conditions and maladaptive social cognitions (e.g., intervention materials should contain cancer-specific examples).

Prior to the development of loneliness interventions for cancer populations, cancer-specific tools are needed to assess: (1) loneliness attributed to cancer (i.e., cancer-related loneliness), and (2) negative social expectations related to cancer that may precipitate and sustain loneliness. These measures could advance loneliness research in multiple respects. First, a tool assessing loneliness attributed to cancer could allow us to identify patients who may warrant a cancer-specific loneliness intervention. In addition, researchers could assess whether the intervention reduced cancer-related loneliness.

Second, a measure of patients' negative social expectations related to cancer could contribute to theory development and clinical care. To my knowledge, a measure of negative social expectations associated with loneliness has not been developed for any population. If I found that negative social expectations are correlated with loneliness, it would provide further support for theory linking these variables (Cacioppo & Hawkley, 2009). Furthermore, therapists could select negative social cognitions upon which to intervene based on item responses. Following the intervention, researchers could empirically evaluate whether reduced negative social expectations mediate the effects of a cognitive intervention on cancer patients' loneliness.

To address the need for cancer-specific tools, I developed and tested measures of cancer-related loneliness (aim 1) and cancer-related negative social expectations (aim 2) in the current project. The goal of the cancer-related loneliness measure (i.e., Cancer Loneliness Scale) is to assess patients' loneliness attributed to cancer. The goal of the negative social expectations measure (i.e., Cancer-related Negative Social Expectations Scale) is to assess negative social cognitions related to patients' cancer experiences. Development of the item pools for testing was guided by theory, prior research, and qualitative interviews conducted as part of this project. First, I developed the item pool for the Cancer Loneliness Scale based on loneliness theory (Cacioppo & Hawkley, 2009; Cacioppo et al., 2006; Cutrona, 1982; Peplau & Perlman, 1982), previous general loneliness measures (de Jong-Gierveld, 1987; de Jong-Gierveld & Van Tilburg, 2006; Russell, 1996; Vincenzi & Grabosky, 1987), and qualitative studies of loneliness in cancer patients and survivors (Rosedale, 2009; Sand et al., 2008). For example, qualitative work suggests that reduced illness-related discussion with family members over time contributes to patients' feelings of loneliness (Sand et al., 2008). Therefore, one item in the Cancer Loneliness Scale item pool was "How often do you feel that others cannot provide the support that you need to deal with your cancer?" Next, qualitative interviews were conducted to obtain cancer patients' feedback on the Cancer Loneliness Scale items. Decisions about item revision were subsequently made based on patient feedback. Additionally, during the qualitative interviews cancer patients were asked to describe their experiences of loneliness, including thoughts and situations evoking these feelings. Based on the qualitative interview data, theory (J. Beck, 2011; Cacioppo & Hawkley, 2009; Lepore, 2001), and prior research on cancer patients' loneliness (Mosher et al., 2012; Rosedale, 2009; Sand et al., 2008), I developed the item pool for the Cancer-related Negative Social Expectations Scale.

To test the construct validity of the measures, I examined a number of theory-driven relationships between the measures and social, psychological, and somatic variables in a new, larger sample of cancer patients who completed mailed questionnaires. Regarding the Cancer Loneliness Scale, most of these theoretical relationships were hypothesized to mirror those found in the general loneliness literature and, thus, hypotheses were based on loneliness theory (Cacioppo & Hawkley, 2009; Cacioppo et al., 2006; Cutrona, 1982; Peplau & Perlman, 1982) and prior research on loneliness (Cacioppo et al., 2006; Hawkley & Cacioppo, 2003; Mosher et al., 2012; Russell, 1996). First, I expected cancer-related loneliness to be positively related to anxiety and depressive symptoms, consistent with theory and prior research on general loneliness (Cacioppo & Hawkley, 2009; Cacioppo et al., 2006; Hawkley & Cacioppo, 2003; Peplau & Perlman, 1982). Second, I expected cancer-related loneliness to be positively associated with general loneliness, as dissatisfaction with relationships is central to both types of loneliness. Third, I expected cancer-related loneliness to be positively related to social constraints and negatively related to social support because social cognitive processing theory (Lepore, 2001) suggests that the social environment impacts psychological adjustment. In support of this prediction, several studies have found that social support and social constraints are associated with general loneliness in cancer patients (Deckx et al., 2014; Mosher et al., 2012; Sahin & Tan, 2012; Yildirim & Kocabiyik, 2010). Fourth, I expected cancer-related loneliness to be negatively related to quality of life because loneliness has been consistently associated with poor health-related outcomes in cancer patients and the general population (Hawkley & Cacioppo, 2003; Jaremka, Andridge, et al., 2014; Pehlivan et al., 2012). Lastly, I expected cancer-related loneliness to be negatively associated with the number of cancer patient confidants, but unrelated to the size of one's total network of family and friends. According to theory, loneliness is not a result of actual isolation or one's number of social network members, but instead relates to dissatisfaction with relationships (Peplau & Perlman, 1982; Russell, 1996). Accordingly, loneliness has generally been unrelated to social network size (Peplau & Perlman, 1982; Russell, 1996). However, in qualitative work, cancer patients have reported that having more contact with other cancer patients reduced their feelings of loneliness (Egestad, 2013). Contact with other cancer patients might lead to decreases in cancer-related loneliness because it provides an opportunity for patients to communicate with others who are going through similar experiences (e.g., heightened existential concerns). This communication might normalize their experiences, leading them to feel more connected to others. Feeling disconnected is a central aspect of loneliness and, therefore, increased social connection with other cancer patients is likely to reduce feelings of cancer-related loneliness.

To test the construct validity of the Cancer-related Negative Social Expectations Scale, I examined theoretical relationships between the new measure and social and psychological variables. First, I expected negative social expectations to be positively correlated with loneliness and cancer-related loneliness based on theory linking negative social expectations to loneliness (Cacioppo & Hawkley, 2009) and prior research showing loneliness-reducing effects of interventions targeting social cognitions in the general population (Masi et al., 2010). Second, I expected negative social expectations to be positively correlated with anxiety and depressive symptoms, as negative thought patterns are theorized to underlie anxiety and depressive disorders (A. Beck, 1970; Clark & Beck, 1989). Third, I hypothesized that negative social expectations would be positively associated with somatic symptoms and negatively associated with quality of life, as these expectations are theorized to impact health outcomes by activating neurobiological mechanisms that increase HPA axis dysfunction and reduce sleep quality (Cacioppo & Hawkley, 2009). Finally, I expected negative social expectations to be positively correlated with social constraints and negatively correlated with emotional support. Negative social expectations are theorized to increase social behaviors that elicit negative social interactions (Cacioppo & Hawkley, 2009).

The specific aims and hypotheses are as follows:

Qualitative Aim 1: To develop a new measure of cancer-related loneliness ("Cancer Loneliness Scale") and obtain feedback on the items from cancer patients.

Qualitative Aim 2: To develop a new measure that identifies negative social expectations in cancer patients ("Cancer-related Negative Social Expectations Scale").

Quantitative Aim 3. To evaluate the psychometric properties of the Cancer Loneliness Scale in a diverse sample of cancer patients.

Hypothesis 3.1: The Cancer Loneliness Scale will be unidimensional as assessed by confirmatory factor analysis.

Hypothesis 3.2: The Cancer Loneliness Scale will demonstrate an internal consistency coefficient of 0.70 or above.

Hypothesis 3.3: Construct validity of the Cancer Loneliness Scale will be demonstrated by support of the following theoretical relationships:

(a) Cancer-related loneliness will be positively related to general loneliness, social constraints, psychological symptoms (i.e., anxiety and depression), and somatic symptoms (i.e., sleep disturbance, pain, fatigue).

(b) Cancer-related loneliness will be negatively related to mental and physical quality of life, emotional support, and the number of cancer patient confidants.

(c) Cancer-related loneliness will be unrelated to general social network size.

Exploratory Quantitative Aim 4. To evaluate the psychometric properties of the Cancer-related Negative Social Expectations Scale in a diverse sample of cancer patients.

Goal 4.1: Based on findings of the qualitative study, conduct confirmatory factor analyses to determine the dimensionality of the Cancer-related Negative Social Expectations Scale.

Goal 4.2: To explore internal consistency coefficients for the Cancer-related Negative Social Expectations Scale dimensions identified in Goal 4.1.

Goal 4.3: To explore whether the following theoretical relationships are found to support the construct validity of the Cancer-related Negative Social Expectations Scale:

(a) Negative social expectations will be positively related to general loneliness, cancer-related loneliness, social constraints, psychological symptoms (i.e., anxiety and depression), and somatic symptoms (i.e., sleep disturbance, pain, fatigue).

(b) Negative social expectations will be negatively related to mental and physical quality of life and emotional support.

QUALITATIVE STUDY METHODS

Participants

Following institutional review board approval, cancer patients were recruited from a hematology/oncology clinic at the Indiana University Simon Cancer Center. Eligibility status was determined by medical chart review, consultation with patients' oncologists, and observation during the informed consent process. Eligibility criteria for the study included: (1) having a diagnosis of multiple myeloma or non-Hodgkin's lymphoma; (2) currently undergoing curative or palliative treatment for cancer; (3) being 18 years of age or older; (4) being able to read and write in English; (5) having no serious cognitive impairment (based upon the patient's ability to describe the study after it had been explained during the informed consent process); and (6) being scheduled for an upcoming appointment in the oncology clinic. Patients who were undergoing treatment for multiple myeloma or non-Hodgkin's lymphoma were interviewed because many receive treatments involving prolonged isolation, such as hematopoietic stem cell transplantation (HSCT), which may be expected to precipitate loneliness. In addition, others' limited understanding of these less common cancers may contribute to patients' feelings of loneliness.

Measures

Demographic and Medical Characteristics

The following characteristics were collected from participants' medical records following informed consent: age, gender, cancer type(s), date(s) of diagnosis, cancer treatments received (e.g., surgery, radiation, chemotherapy), and cancer stage(s) (i.e., early vs. late/advanced). The following characteristics were collected via participant self-report: marital status, race/ethnicity, education level, employment status, and health insurance status.

Loneliness

General loneliness was measured by the UCLA Loneliness Scale-Version 3 (Russell, 1996). This 20-item unidimensional scale is the most widely used measure of general loneliness in research. The measure uses a 4-point Likert-type scale with responses ranging from 1 (*never*) to 4 (*always*). A sample item is "How often do you feel that people are around you but not with you?" The UCLA Loneliness Scale has shown excellent reliability across studies, including studies of cancer patients (e.g., Fogel et al., 2002; Yildirim & Kocabiyik, 2010), with one meta-analysis of alpha reliability coefficients across populations finding a mean alpha coefficient of 0.92 (SD = .03, range = 0.86-0.95; Vassar & Crosby, 2008). In the current study, internal consistency reliability was excellent (α=0.89). Excellent validity evidence is also available in general population and cancer patient samples (Jaremka, Andridge, et al., 2014; Mosher et al., 2012; Russell, 1996).

PROMIS Measures of Depressive and Anxiety Symptoms

NIH-funded Patient Reported Outcomes Measurement Information System (PROMIS) measures were used to assess depressive and anxiety symptoms. PROMIS measures have undergone rigorous reliability and validity testing (e.g., Cella et al., 2010; Cella et al., 2007; Magasi et al., 2012) and were developed with cancer populations in mind (Garcia et al., 2007). Depressive and anxiety symptoms during the past 7 days were assessed with the PROMIS 4-item Depression measure and 4-item Anxiety measure, respectively (Choi, Reise, Pilkonis, Hays, & Cella, 2010; Pilkonis et al., 2011). The measures use a 5-point Likert-type scale with responses ranging from 1 (*never*) to 5 (*always*). Two 4-item composite scores were calculated by averaging relevant items, with higher scores indicating greater depressive and anxiety symptoms. A sample depression item is “In the past 7 days, I felt hopeless,” and a sample anxiety item is “In the past 7 days, my worries overwhelmed me.” In the current study, internal consistency reliability was excellent for the depression measure (α=0.82) and good for the anxiety measure (α=0.75).

Social Network Characteristics

Four items adapted from the Social Network Index (Cohen, Doyle, Skoner, Rabin, & Gwaltney, 1997) were used to assess social network characteristics. The primary content of Cohen and colleagues’ items was retained, but the social network categories (e.g., relatives, friends) differed. The items included: (1) “How many relatives do you see or talk to on the phone at least once every 2 weeks?”; (2) “How many friends do you see or talk to on the phone at least once every 2 weeks?”; (3) “How many co-workers do you see or talk to on the phone at least once every 2 weeks?"; and (4) How many cancer patients or survivors do you see or talk to on the phone at least once every 2 weeks?" Participants who were not currently employed were instructed to skip the item on coworkers.

Cancer-related Loneliness

Participants were asked to provide feedback on the format and content of 15 potential items for the Cancer Loneliness Scale (see Appendix A). Some of the items were tailored from the UCLA Loneliness Scale-Version 3 and other loneliness measures (de Jong-Gierveld, 1987; Russell, 1996; Vincenzi & Grabosky, 1987), whereas other items were developed based on loneliness theory (Cacioppo & Hawkley, 2009; Cacioppo et al., 2006; Cutrona, 1982; Peplau & Perlman, 1982) and qualitative research on loneliness in cancer patients (Rosedale, 2009; Sand et al., 2008). A 5-point Likert-type scale with responses ranging from 1 (*never*) to 5 (*always*) was used. These responses were selected because they are similar to those used by the well-validated PROMIS measures, which were described previously. Experts in scale development, loneliness, and social aspects of cancer reviewed the items before they were used in the present qualitative study.

Procedure

Medical Record Screening Procedures

A waiver of HIPAA authorization was obtained in order to review electronic medical records of patients who were scheduled for an upcoming appointment with collaborating oncologists at the Indiana University Simon Cancer Center. Patients' age, cancer diagnosis, and treatment status were determined from medical records in order to identify potentially eligible patients prior to recruitment (see Appendix B for screening form).

Recruitment Procedures

Cancer patients were recruited from the hematology/oncology clinic at the Indiana University Simon Cancer Center. I used purposive sampling (Berg, 2004) based on patient gender and age (≥65 years vs. <65 years) to ensure approximately equal numbers of demographic subgroups. Following approval from the patient's oncologist, I approached the patient before or after his or her oncology clinic appointment. The informed consent process occurred in a private room in the clinic. I described the study, reviewed the consent and authorization forms (see Appendix C for consent form), answered questions, and invited patients to participate. During the informed consent process, I asked the patient to verbalize his or her understanding of the study. If the patient had been unable to clearly describe the study, he or she would have been considered ineligible due to likely cognitive impairment or language difficulties. If interested, eligible patients signed the informed consent and authorization forms prior to study participation. Medical record data were collected after completion of informed consent and authorization forms (see Appendix D for medical record data collection form).

Participants first completed a brief self-report paper questionnaire in clinic (see Appendix E for questionnaire). The questionnaire assessed demographic and medical characteristics, general loneliness, depressive and anxiety symptoms, and characteristics of the participant's social network. I was available to answer any questions. The questionnaire took approximately 5 minutes to complete. After completing the questionnaire, the participant handed it to me, and I checked it for omitted item responses. If there were omissions, I asked the participant whether he or she intended to skip the items. Subsequently, I conducted a brief audiotaped interview with the participant using a semi-structured interview guide (see Appendix F for interview guide). The goals of the interview were: (1) to identify cognitions associated with participants' loneliness; and (2) to obtain feedback on the cancer-related loneliness items. First, I provided participants with the following definition of loneliness: "loneliness means feeling isolated or disconnected from others around you. It isn't about how *much* time you spend with others or how *many* friends you have, but more about how connected you feel with others overall." Then I asked them to describe any experiences of loneliness since their cancer diagnosis. I probed for any situations precipitating their loneliness and thoughts experienced while feeling lonely (e.g., "What thoughts were going through your head as you had this experience?"). Throughout the interview, I asked follow-up questions to obtain a detailed narrative. Next, I showed participants the cancer-related loneliness items (see Appendix A for handouts) and asked them to circle items that did not make sense, were not clear, or were missing important content. Afterwards, we discussed each item that they circled. The interviews ranged from 10 to 30 minutes in length. In total, the questionnaire and interview took up to 35 minutes. After completing the interview, participants were given a $25 Target gift card for their participation.

An iterative sampling process (i.e., alternating between data collection and analysis) was used until saturation was achieved. Saturation is defined as “the point in data collection and analysis when new information produces little or no change to the codebook” (Guest, Bunce, & Johnson, 2006, p. 65). Data collection was complete when saturation had been reached. Prior research suggests that saturation generally occurs after data from 12 participants have been analyzed (Guest et al., 2006).

Data Storage and Data Entry

I entered and checked all data. Paper questionnaires and consent forms are stored in a locked filing cabinet in a lockable office in LD 134.

Analyses

Preliminary Analyses of Quantitative Data

Descriptive statistics (i.e., means, standard deviations, frequencies, ranges) were calculated to characterize the sample with respect to demographics, general loneliness, depressive and anxiety symptoms, and social network qualities.

Procedure for Qualitative Analysis

Interviews were transcribed verbatim and transferred to Atlas.ti for analysis. First, a basic content analysis was used to analyze the interview data regarding qualitative aim 1 (i.e., obtaining feedback on items from the Cancer Loneliness Scale). Content analysis is a descriptive, systematic coding and categorization process by which inferences are made from qualitative data (Berg, 2004; Vaismoradi, Turunen, & Bondas, 2013). This form of analysis is not typically based on theory. Then a theoretical thematic analysis, defined as "a method for identifying, analysing, and reporting patterns (themes) within data" (Braun & Clarke, 2006, p. 6), was used to analyze data regarding qualitative aim 2 (i.e., identifying cognitions to inform the Cancer-related Negative Social Expectations Scale). Specifically, the analysis was guided by loneliness theory (Cacioppo & Hawkley, 2009; Cacioppo et al., 2006; Peplau & Perlman, 1982) such that the analytic goal was to identify thoughts that may have precipitated loneliness. For analyses addressing qualitative aims 1 and 2, an iterative sampling process was used; thus, two coders (Dr. Mosher and I) generated codes independently and met on a regular basis to discuss them (i.e., after the first 3 interviews and then after every 4 interviews). Discrepancies between coders were discussed and reconciled. Data collection was complete when we agreed that saturation had been achieved. Next, we categorized the codes into broader themes. The themes were checked to ensure that they were internally consistent and distinguishable from one another. The themes informed item adjustment and development.

QUALITATIVE STUDY RESULTS

Preliminary Analyses

Seventeen patients were approached regarding this study. All 17 were eligible, and 15 agreed to participate in the study (an 88% response rate). Reasons for patient refusal included discomfort being audiotaped and insufficient time to complete the interview. As shown in Appendix G, participants were primarily Caucasian (14/15) with a mean age of 63 (*SD* = 12; range = 43-77 years). Approximately half of the participants were male (8/15) and approximately half were diagnosed with multiple myeloma (8/15). The majority (10/15) were diagnosed with late-stage disease. The average time since the cancer diagnosis was 2.9 years (*SD* = 3.2 years; range = 0.2-9.4 years). On average, participants reported that they rarely felt lonely on the UCLA Loneliness Scale. Additionally, participants' scores on the depressive and anxiety symptom measures suggested that, on average, they had low levels of depressive symptoms (mean = 2.1; *SD* = 2.1; range = 0-6) and anxiety (mean = 2.7; *SD* = 2.3; range = 0-7), respectively. The average numbers of relatives, friends, coworkers, and other cancer patients that participants reported seeing or talking to on the phone at least once every 2 weeks were 5.6 (*SD* = 4.6; range = 0-18), 9.3 (*SD* = 12.6; range = 0-50), 9.0 (*SD* = 5.9; range = 1-20), and 1.2 (*SD* = 1.4; range = 0-5), respectively.

Feedback on the Cancer Loneliness Scale

The first set of analyses addressed Qualitative Aim #1, which was to obtain feedback from cancer patients on the potential Cancer Loneliness Scale items. Overall, most participants stated that the potential items for the Cancer Loneliness Scale were clear and easy to understand and that they had no suggestions regarding content or additional items. However, some participants had suggestions for improving the measure. Specific suggestions included adding items to assess context, adding items about positive social experiences, using less extreme language, and defining the word "empty." Each of these suggestions is described below.

Add Items to Assess Context

Several participants said that adding items to assess context would provide a more comprehensive understanding of cancer patients' loneliness experiences. For instance, a couple of participants said that their loneliness had fluctuated over their illness trajectory and that assessing perceptions of loneliness at different time points would provide more information. As one participant said,

> I would add [instructions to assess loneliness at the] . . . time . . . that I was in the hospital and the time that I was home. I have been out of the hospital for five months, so I answer these questions very much like I am home with my family and have a good support system. I'm wondering if . . . they asked me how I felt when I was in the hospital, if it might not be a very different answer.

Participants suggested that I assess other types of contextual information as well, such as social support and the presence of non-cancer stressors that might impact a person’s level of loneliness. For example, in the following quote, one participant recommended assessing marital status:

> It might be helpful if you get a feel of their status-- whether they’re widowed, divorced-- that aspect of it. Because being single, never married, for example, or recently widowed, that could certainly impact this.

Add Items to Assess Positive Social Experiences

Some participants said it would be important for me to assess positive experiences, including social experiences, related to the cancer diagnosis. As one participant said,

> You’re just getting a picture of all the people who feel down in the dumps. You need to get a picture of the people trying to keep uplifted about [cancer].

Use Less Extreme Language

One participant suggested that using extreme language (i.e., “no one” in item number four) would make the item less relatable to certain respondents, such as herself. She explained:

> [Participant reads item]: “How often do you feel that there is no one you can share.” I mean, I always have my husband and hopefully others have at least one person. But there are not a lot of people [with whom I can share besides my husband] . . .

Define the Word “Empty”

One participant said that she was confused by the word “empty,” which was used in two items (#5 and #13). Specifically, she stated: It’s the empty that I think throws off. Because my immediate thought was well, what do you mean by empty? Do you mean lonely or do you mean like, nothing is inside of me? You know, that’s the kind of thing that I would probably have to sit there and think about and be like, do I feel empty? You know, it’s just . . . a redundant question since you’re asking about if you feel lonely. . . . Just explain what you mean by empty a little bit more. That’s the one that would trip me up, you know, if I was taking the survey.

Thoughts Associated with Loneliness

In addition to obtaining feedback on the potential Cancer Loneliness Scale items for Qualitative Aim #1, I also asked patients to describe thoughts they associated with their loneliness to inform development of the Cancer-related Negative Social Expectations Scale (Qualitative Aim #2). Patients reported a number of thought patterns during times of loneliness. Some of the thought patterns involved negative social expectations, including unmet expectations for visits or questions about their health, the belief that disclosing illness-related information would negatively impact their relationships, and the belief that others do not understand their cancer-related experiences. Other thought patterns that patients associated with their loneliness include perceptions of socially constraining behaviors from others and thoughts about death. These thoughts are described below.

Negative Social Expectations Associated with Loneliness

Others Do Not Visit or Ask Questions as Often as I Expect

Many participants had unmet expectations for visits and calls from family and friends, which resulted in feelings of loneliness. Perceiving a lack of care and concern from others during conversations also contributed to loneliness. As one woman stated,

> My children haven't asked me any questions [about the cancer] . . . they just . . . change the subject. I don't know if they just don't want to talk about it. It does cross my mind, "Why aren't they asking any questions?"

My Relationships Would Change for the Worse if I Disclosed My Health Status

Some participants believed that informing others of their cancer diagnosis, treatment, or symptom severity would lead to unwanted changes in their relationships. Withholding this information often led to feelings of isolation, as illustrated by the following quote from a woman who did not initially disclose her diagnosis:

> I felt isolated there at first, not wishing to discuss it [the cancer] and sometimes just the stigma of having cancer I think scares people away from you… people may not want to come around you or just be scared to approach or be afraid of what to say to you.

For other participants, a lack of cancer-related disclosure was motivated by a desire to protect others from distress, as illustrated by the following statement:

> [My husband] gets real depressed, so I . . . don’t share too much of the information with him. . . . From these scans, year over year, they seem to get worse every time. . . . But I can’t share that with him because he’s going to be really upset if I told him. . . . It’d be better if I did have somebody to share it with. . . I don’t [think] I can do that.

Others Cannot Understand My Cancer-related Experiences

Participants reported feeling misunderstood by others during times of loneliness. Specifically, some patients felt that others could not understand various cancer-related experiences, such as the process of undergoing cancer treatment and its physical side effects. One patient who underwent two HSCTs described this experience:

> Sometimes you are misunderstood. People don’t know. They don’t understand my cancer. . . people come up to you and say, “You don’t look sick.” I’ll tell you, only after my second transplant did I really look sick because. . . I lost tons of weight. That is a question where you sit there and think, “I don’t know quite what I am supposed to say to that.” Or people who don’t understand the cancer and think you had this transplant and now I’m well. Well, you don’t want to dwell on it and say, “It doesn’t go away. I’m not going to get better.”

Other Thoughts Associated with Loneliness

Others Treat Me Poorly Because of My Cancer

Loneliness was also associated with perceptions of experiencing socially constraining behaviors from family and friends related to their cancer diagnosis. For example, some participants said that loved ones criticized them or blamed them for their cancer diagnosis. Following this criticism, participants often avoided sharing their feelings about the cancer, which heightened feelings of loneliness. In addition, many participants stated that family and friends acted in a nervous or uncomfortable manner around them, especially when discussing their cancer. As one woman said,

> My husband and kids, after hearing about [the cancer], would sometimes feel awkward around me and that would make me feel lonely . . . kind of left out.

My Time Might be Limited

Some participants reported a new awareness of their mortality following their cancer diagnosis. Existential questions such as “Why me?” and “How much longer do I have to live?” led to feelings of disconnection from others who did not face the same challenges. Although this existential awareness increased some patients’ desire to spend time with family and friends, others felt that they did not have time for certain relationships. One man described his withdrawal from others:

> I’ve chosen . . . to be isolated . . . I have . . . isolated myself more and more from people I know. . . . It’s almost like I have the feeling that I just don’t have time . . .

> to maintain these relationships. . . . Of course, when you're sixty and you have cancer . . . your own mortality becomes a significant issue . . . . I just don't have . . . time, however long I'll live. . . . The cancer does play a role because it becomes a limiting factor . . . again, the cancer has put an exclamation point on that eventuality, that we're all going to die, right? . . .It's really put an exclamation point on that for me.

QUALITATIVE STUDY DISCUSSION

The goals of the current study were to (1) obtain feedback on the Cancer Loneliness Scale (Qualitative Aim #1), and (2) identify thoughts associated with cancer patients' loneliness to inform the development of a measure of cancer-related negative social expectations (Qualitative Aim #2). First, I will discuss participant feedback on the Cancer Loneliness Scale and my decisions regarding revisions to the scale. Next, I will discuss thoughts that patients associated with their loneliness. Third, I will discuss how I developed items for the Cancer-related Negative Social Expectations Scale based on the present qualitative findings and prior research and theory. Finally, I will discuss study limitations and implications for theory and future research.

Feedback on the Cancer Loneliness Scale

Overall, participants said that they liked the Cancer Loneliness Scale; however, some suggestions for improvement were provided. For instance, multiple participants suggested adding items to assess context and positive social experiences. Participants said that greater contextual knowledge would help researchers better understand circumstances surrounding loneliness. In addition, some participants felt that assessing positive social experiences would provide useful supplemental information. I agreed with these comments and included other variables (e.g., social support, time since diagnosis) to assess context and positive social experiences in the quantitative study detailed below. In addition, one participant suggested using less extreme language (i.e., omitting “no one”) in item #4, and one participant suggested that we define the word “empty” in items #5 and #13. Because only one participant suggested each change, I decided to retain the items’ current wording and be attentive to those items’ psychometric performance in the subsequent quantitative study. Thus, no changes were made to the Cancer Loneliness Scale based on participant feedback.

Thoughts Associated with Loneliness

Many patients identified negative social cognitions associated with their loneliness. These results are consistent with loneliness theory suggesting that negative social cognitions may precipitate or sustain loneliness (Cacioppo & Hawkley, 2009). We identified five themes, or thought patterns, that patients associated with their loneliness. First, I will discuss thought patterns involving negative social expectations and then I will discuss other thought patterns.

Negative Social Expectations Associated with Loneliness

First, some participants reported that visits from family and friends and questions about their illness did not occur as often as expected, which led to feelings of loneliness. Similarly, one qualitative study found that cancer patients felt devalued when they had fewer conversations with family members concerning their illness over time (Sand et al., 2008). The present finding is also consistent with the definition of loneliness as the discrepancy between an individual’s expectations for social support and perceived social support (Peplau & Perlman, 1982; Russell, Peplau, & Cutrona, 1980). That is, patients in this study reported feeling lonely when their social expectations were not met.

Second, some patients were concerned that disclosing their health status would negatively impact their relationships. Some patients with this thought pattern experienced distress and disconnection from others when they failed to discuss cancer-related concerns. This finding is consistent with social cognitive processing theory (Lepore, 2001; Lepore & Revenson, 2007). Specifically, non-disclosing patients do not have the opportunity to process cancer-related information with others, which has been found to facilitate psychological adjustment (Lepore & Helgeson, 1998; Manne et al., 2004; Mosher et al., 2012). Relatedly, protective buffering (e.g., hiding concerns and worries in an attempt to prevent others from experiencing distress) (Manne et al., 2007), has been associated with poorer psychological adjustment and lower levels of relationship satisfaction in cancer patients (Langer et al., 2009; Manne et al., 2007). Additionally, in a qualitative study, post-treatment breast cancer patients reported feeling lonely when they withheld their feelings to protect others (Rosedale, 2009).

Third, some patients believed that others could not understand their cancer-related experiences and subsequently felt lonely. To date, limited research has studied the relationship between loneliness and feeling misunderstood by others. Specifically, in a qualitative study of post-treatment breast cancer patients, patients said that others' misunderstanding of their cancer-related changes made them feel lonely and anxious (Rosedale, 2009). Relatedly, one quantitative study found that healthy spouses' relationship satisfaction, a concept related to loneliness, was associated with feeling understood by their partner (Weger, 2005).

Other Thoughts Associated with Loneliness

Some patients also believed that others' socially constraining behavior towards them contributed to loneliness. These socially constraining behaviors included criticism, avoidance, or acting in a nervous or uncomfortable manner around them. Findings converge with theory and research linking social constraints, including perceptions of others' criticism, to loneliness (Lepore, 2001; Mosher et al., 2012). Specifically, social cognitive processing theory posits that social constraints impede the cognitive processing of cancer-related stress, which in turn hinders psychological adjustment (e.g., increases loneliness) (Lepore, 2001; Lepore & Revenson, 2007). Accordingly, one study found that greater social constraints were associated with greater loneliness among cancer patients who underwent HSCT (Mosher et al., 2012).

Lastly, some patients said that existential thoughts, including a newfound awareness of their mortality and unpredictable future, contributed to their loneliness. Furthermore, many patients felt that others did not share their heightened awareness about mortality. These findings are comparable to those of Rosedale (2009) who reported that breast cancer survivors felt others did not understand ongoing concerns about mortality and their future. Furthermore, a novel finding of the current study was that thoughts about mortality may contribute to loneliness by decreasing interest in maintaining relationships. Specifically, some patients prioritized other activities over certain relationships when they perceived their time as limited, which led to feelings of isolation. Patients' withdrawal from certain relationships is consistent with socioemotional selectivity theory which posits that one's perception of how much time one has left impacts social goals (Carstensen, Isaacowitz, & Charles, 1999). Consistent with this theory, one study indicated that cancer patients who perceived themselves as having more time left showed greater interest in interacting with new social contacts compared to patients who perceived themselves as having less time (Pinquart & Silbereisen, 2006). Our finding is also consistent with clinicians' observation that, as cancer patients' symptom burden increases and their mortality becomes more salient, they often change their priorities. Many previously meaningful relationships may be discarded by necessity.

Development of the Item Pool for the Cancer-Related Negative Social Expectations Scale

Based on the five themes or thought patterns identified in this study as well as theory and literature described previously (Cacioppo & Hawkley, 2009; Lepore, 2001; Lepore & Revenson, 2007; Mosher et al., 2012; Rosedale, 2009; Russell, 1996), I identified five domains for the Cancer-Related Negative Social Expectations Scale, including: (1) expecting others to listen or be available as often as desired; (2) expecting a lack of understanding of cancer-related concerns; (3) expecting that others will not understand existential thoughts; (4) expecting that the disclosure of cancer-related concerns will burden others; and (5) expecting that disclosure of their diagnosis or cancer-related concerns will change their relationships for the worse. A list of the items developed to assess each domain is provided in Appendix H. Current study themes and prior research and theory related to each domain of this measure are provided below.

Domain 1: Expecting Others to Listen or be Available Whenever the Patient Needs Them

Domain 1 was developed based on the themes “others do not visit or ask questions as often as I expect” and “others treat me poorly because of my cancer” as well as social cognitive processing theory and prior research discussed previously (Lepore, 2001; Lepore & Revenson, 2007; Mosher et al., 2012; Peplau & Perlman, 1982; Russell et al., 1980; Sand et al., 2008). A sample item is “I expect other people to listen to me whenever I want to talk about my cancer.”

Domain 2: Expecting a Lack of Understanding of Cancer-related Concerns

Domain 2 was developed based on the theme “others do not understand my cancer-related experiences” as well as prior literature discussed previously (Rosedale, 2009; Weger, 2005). A sample item is “Other people could not truly understand how I feel about my cancer diagnosis.”

Domain 3: Expecting That Others Will Not Understand Existential Thoughts

Domain 3 was developed based on the theme “my time might be limited,” representative of existential thoughts, and prior research discussed previously (Rosedale, 2009). A sample item is “Other people would not understand my thoughts about death since my cancer diagnosis.”

Domain 4: Expecting Sharing Cancer-related Concerns to Burden Others

Domain 4 was developed based on the theme “my relationships would change for the worse if I disclosed my health status” as well as social cognitive processing theory and prior research (Langer et al., 2009; Lepore, 2001; Manne et al., 2007; Mosher et al., 2012; Rosedale, 2009). A sample item is “If I shared my concerns about cancer with other people then it would be too hard on them.”

Domain 5: Expecting Disclosure of Their Diagnosis or Cancer-related Concerns to Change Their Relationship for the Worse

Domain 5 was developed based on the theme “my relationships would change for the worse if I disclosed my health status” as well as social cognitive processing theory and prior research (Lepore, 2001; Lepore & Revenson, 2007). A sample item is “If I shared my concerns about cancer with other people then they might hurt me with their reactions.”

Limitations

Limitations of this study should be noted. Although the sample was diverse with respect to gender, education level, disease stage, and time since diagnosis, participants were primarily Caucasian patients from one institution in the Midwest. Exploring loneliness-related thoughts in cancer patients from diverse cultural groups and geographic regions is an important direction for future research. In addition, loneliness has been found to be greater at some points in the cancer trajectory than others (Deckx et al., 2014), and retrospective reporting may not fully capture these changes in loneliness and its precipitants. Furthermore, interviews were relatively brief in length (10-30 minutes) because they were completed in a busy clinic setting. Longitudinal data collection and more in-depth interviews would provide more detailed information about loneliness experiences over different phases of the disease trajectory and enhance generalizability. In addition, although prior research suggests a sample size as small as 12 is sufficient for reaching saturation (Guest et al., 2006), it is possible that more themes may have been obtained with a larger sample.

Summary and Implications

The outcome of the current study is item pools for the Cancer Loneliness Scale and the Cancer-related Negative Social Expectations Scale. To my knowledge, no one has previously developed a measure of cancer-related loneliness or a measure of negative social expectations for any population. In future studies, the Cancer Loneliness Scale could be used as a screening tool to identify patients warranting a cancer-specific loneliness intervention as well as an intervention outcome. Furthermore, the Cancer-related Negative Social Expectations Scale could be used to provide an initial test of theory linking negative social expectations to loneliness (Cacioppo & Hawkley, 2009). If negative social expectations are indeed associated with loneliness, interventionists could use patients’ responses to the measure to select cognitions upon which to intervene. Additionally, the negative social expectations measure could be used to assess whether changes in these expectations mediate the effect of a cognitive intervention on loneliness. Before these measures are used, psychometric testing in a large sample of cancer patients is required. Thus, the goal of my subsequent quantitative study is to examine the performance of individual items and the measures’ factor structures, reliability, and validity in a large sample of cancer patients.

QUANTITATIVE STUDY METHODS

Participants

Following institutional review board approval, cancer patients were recruited from the Indiana Tumor Registry. Eligibility status was determined by medical chart review and observation during a telephone-based informed consent process. Eligibility criteria for the study included: (1) having received a cancer diagnosis in 2013 or 2014; (2) being 18 years of age or older at the time of informed consent; (3) being able to read and write in English; (5) no evidence of serious cognitive impairment (based upon medical chart review and interactions with the patient during the informed consent process); and (6) having received care for cancer at an Indiana University Health Hospital during 2013 or 2014. Patients whose primary cancer diagnosis was brain cancer were excluded due to possible cognitive or personality changes related to their diagnosis. Nearly all cancer types and stages were eligible because loneliness has not been found to differ by cancer type or stage (Deckx et al., 2014). Furthermore, enrolling patients diagnosed within the past 2 years increases the internal and content validity of the measure. Specifically, if individuals no longer identify with their cancer diagnosis, they may have difficulty responding to items referring to their disease.

Measures

Demographic and Medical Characteristics

The following characteristics were collected from participants' medical records following informed consent: age, gender, cancer type, date of diagnosis, cancer treatments received (e.g., surgery, radiation, chemotherapy), and cancer stage (i.e., early vs. late/advanced). The following characteristics were collected via participant self-report: marital status, race/ethnicity, education level, employment status, and health insurance status.

PROMIS Measures of Social and Health-related Outcomes

NIH-funded Patient Reported Outcomes Measurement Information System (PROMIS) measures were used to assess emotional support, psychological symptoms, somatic symptoms, and quality of life. The use of PROMIS measures is being encouraged by the NIH and has many advantages. For one, PROMIS measures have undergone rigorous reliability and validity testing (Cella et al., 2010; Cella et al., 2007; Magasi et al., 2012). Additionally, standardized T-scores facilitate comparisons with general population norms. Although reliability and validity evidence with cancer patients has yet to be obtained for all PROMIS measures, these measures were developed with cancer populations in mind. Specifically, cancer patients provided input so as to ensure the measures' relevance for cancer patients (Garcia et al., 2007). Full details on PROMIS measures are available at www.nihpromis.org.

Emotional Support

Emotional support was assessed with the 4-item Emotional Support measure (Hahn et al., 2014). The measure uses a 5-point Likert-type scale with responses ranging from 1 (*never*) to 5 (*always*). A sample item is “I have someone who will listen to me when I need to talk.” A total score was calculated by summing the four items, with higher scores indicating greater emotional support. Although, to my knowledge, there is no published reliability or validity evidence for the 4-item version of this measure in any population, in the current study, internal consistency reliability was excellent (α=0.95).

Depressive Symptoms

Depressive symptoms were assessed with the 4-item Depression measure (Choi et al., 2010; Pilkonis et al., 2011). The measure uses a 5-point Likert-type scale with responses ranging from 1 (*never*) to (*always*). A sample item is “In the past 7 days, I felt hopeless.” A total score was calculated by summing the four items, with higher scores indicating greater depressive symptoms. Adequate reliability and validity evidence has been obtained for PROMIS depression items in cancer patient samples (Badr, Smith, Goldstein, Gomez, & Redd, 2015; Baum, Basen-Engquist, Swartz, Parker, & Carmack, 2014; Phelan et al., 2013). In the current study, internal consistency reliability was excellent (α=0.93).

Anxiety Symptoms

Anxiety symptoms were assessed with the 4-item Anxiety measure (Pilkonis et al., 2011). The measure uses a 5-point Likert-type scale with responses ranging from 1 (*never*) to 5 (*always*). A sample item is “In the past 7 days, my worries overwhelmed me.” A total score was calculated by summing the four items, with higher scores indicating greater anxiety. Adequate reliability and validity evidence has been obtained for PROMIS anxiety items in cancer patient samples (Badr et al., 2015; Baum et al., 2014). In the current study, internal consistency reliability was excellent (α=0.90).

Pain

The extent to which pain interfered with daily activities was assessed with the 4-item version of the Pain Interference measure (Amtmann et al., 2010). The Pain Interference measure uses a 5-point Likert-type scale with responses ranging from 1 (*not at all*) to 5 (*very much*). A sample item is “How much did pain interfere with your day to day activities?” A total score was calculated by summing the four items, with higher scores indicating greater pain interference. Excellent reliability and validity evidence is available for general population samples (Amtmann et al., 2010). Although the PROMIS pain interference items have been administered to cancer patients (Stukenborg et al., 2014; Wagner et al., 2015; Yost, Eton, Garcia, & Cella, 2011; Zullig et al., 2012), the authors did not publish reliability or validity evidence. In the current study, internal consistency reliability was excellent (α=0.97).

Fatigue

Fatigue severity was assessed with the 4-item version of the Fatigue measure (Lai et al., 2011). The Fatigue measure uses a 5-point Likert-type scale with responses ranging from 1 (*not at all*) to 5 (*very much*). A sample item is "In the past 7 days, how fatigued were you on average?" A total score was calculated by summing the four items, with higher scores indicating greater fatigue. Adequate reliability and validity evidence has been obtained for PROMIS fatigue items in cancer patient samples (Barsevick et al., 2013; Junghaenel, Cohen, Schneider, Neerukonda, & Broderick, 2015; Lai, Crane, & Cella, 2006; Wagner et al., 2015; Yost et al., 2011; Zullig et al., 2012). In the current study, internal consistency reliability was excellent (α=0.95).

Sleep Disturbance

Sleep disturbance was assessed with the 4-item version of the Sleep Disturbance measure (Buysse et al., 2010; Yu et al., 2012). The Sleep Disturbance measure uses two 5-point Likert-type scales. For the first 3 items, responses range from 1 (*not at all*) to 5 (*very much*), and for the fourth item responses range from 1 (*very poor*) to 5 (*very good*). A sample item using the first scale is "In the past 7 days, I had a problem with my sleep." The item using the second scale is "My sleep quality is..." A total score was calculated by summing the four items, after reverse-scoring as needed, with higher scores indicating greater sleep disturbance. Excellent reliability and validity evidence is available for general population samples (Yu et al., 2012). Although the PROMIS sleep disturbance items have been administered to cancer patients in prior studies (Rogers et al., 2015;

Stachler, Schultz, Nerenz, & Yaremchuk, 2014), reliability and validity evidence was not published. In the current study, internal consistency reliability was excellent (α=0.89).

Quality of Life

Quality of life was measured with the 10-item Global Health measure, which can be separated into two, 4-item mental and physical health scales, a 1-item overall health scale, and a 1-item satisfaction with social roles scale (Hays, Bjorner, Revicki, Spritzer, & Cella, 2009). The 4-item mental and physical health scales were used in the current study. Seven of the items use 5-point Likert-type scales with a variety of response options, and one item uses an 11-point visual analog scale. Total mental and physical health scores were calculated according to the instructions described by Hays et al. (2009), with higher scores indicating better mental or physical health. A sample mental health item is "In general, how would you rate your mental health, including your mood and your ability to think?" A sample physical health item is "In general, how would you rate your physical health?" Excellent reliability and validity evidence was reported for the two subscales for one general population sample (Hays et al., 2009). However, although the mental and physical health subscales have been administered to cancer patients in prior research (Weaver et al., 2012), no reliability or validity evidence was published. In the current study, internal consistency reliability for the mental health scale was good (α=0.82), whereas it was poor for the physical health scale (α=0.27). To determine whether one item reduced the physical health scale's alpha, I examined the alpha level with and without each item. When one item was removed (i.e., the 11-point visual analog scale for pain), the alpha increased to 0.84; thus, analyses were conducted with and without the item. Both sets of results are included in the results table, but the results with the 3-item physical health subscale are discussed in the text.

Social Constraints

A 5-item version of the Social Constraints Scale (Lepore, Silver, Wortman, & Wayment, 1996) was used to measure social constraints. The 5-item scale has been adapted for use in cancer patients in several studies (Danhauer et al., 2013; Halbert et al., 2010; Widows, Jacobsen, & Fields, 2000). The measure uses a 5-point Likert-type scale with responses ranging from 1 (*almost never*) to 5 (*almost always*). A sample item is “How often did you feel as though you had to keep your feelings about your cancer to yourself because they made other people uncomfortable?” A total score was calculated by summing the five items, after reverse-scoring as necessary, with higher scores indicating greater social constraints. Evidence of the scale’s validity and acceptable to good internal consistency reliability has been reported in studies of cancer patients (Halbert et al., 2010; Widows et al., 2000). In the current study, internal consistency reliability was good (α=0.80).

Loneliness

General loneliness was measured with the UCLA Loneliness Scale-Version 3 (Russell, 1996). This 20-item unidimensional scale is a widely used measure of general loneliness in research (Vassar & Crosby, 2008). The measure uses a 4-point Likert-type scale with responses ranging from 1 (*never*) to 4 (*always*). A sample item is “How often do you feel that people are around you but not with you?" A total score was calculated by summing the 20 items, after reverse-scoring as necessary, with higher scores indicating greater loneliness. The UCLA Loneliness Scale has shown excellent reliability across studies, including studies of cancer patients (e.g., Fogel et al., 2002; Yildirim & Kocabiyik, 2010), with one meta-analysis finding that the mean alpha coefficient was 0.92 across various populations (SD = .03, range = 0.86-0.95; Vassar & Crosby, 2008). In the current study, internal consistency reliability was excellent (α=0.94). Excellent validity evidence is also available from studies of general population and cancer patient samples (Jaremka, Andridge, et al., 2014; Mosher et al., 2012; Russell, 1996).

Cancer-related Loneliness

Cancer-related loneliness was measured with 15 items developed for the Cancer Loneliness Scale. As discussed previously, some of the items were modified from the UCLA Loneliness Scale-Version 3 and other loneliness measures (de Jong-Gierveld, 1987; Russell, 1996; Vincenzi & Grabosky, 1987), whereas other items were developed based on loneliness theory (Cacioppo & Hawkley, 2009; Cacioppo et al., 2006; Cutrona, 1982; Peplau & Perlman, 1982) and qualitative research on loneliness in cancer patients (Rosedale, 2009; Sand et al., 2008). A 5-point Likert-type scale with responses ranging from 1 (*never*) to 5 (*always*) was used. These response options were selected because they are similar to those used by the PROMIS measures. A sample item is "How often does your cancer diagnosis make you feel isolated from others?"

Negative Social Expectations

Negative social expectations were measured with the 14 items developed for the Cancer-related Negative Social Expectations Scale. As discussed previously, the items were developed based on theory, prior research (Cacioppo & Hawkley, 2009; Lepore, 2001; Lepore & Revenson, 2007; Manne et al., 2007; Mosher et al., 2012; Rosedale, 2009; Sand et al., 2008), and findings from the qualitative study described previously. Items were written to include content in five domains: (1) expecting others to listen or be available whenever the patient needs them; (2) expecting a lack of understanding of cancer-related concerns; (3) expecting that others will not understand existential thoughts; (4) expecting sharing cancer-related concerns to burden others; and (5) expecting disclosure of their diagnosis or cancer-related concerns to change their relationships for the worse. A 6-point Likert-type scale with responses ranging from 1 (*strongly disagree*) to 6 (*strongly agree*) was used. I decided to use six response options such that participants could not select a neutral response (Wolfe & Smith Jr, 2006). A sample item is “If people stopped asking about my cancer, I would think that they don’t care.”

Social Network Characteristics

Four items adapted from the Social Network Index (Cohen et al., 1997) were used to assess social network characteristics. The content of Cohen and colleagues’ items was retained, but the social network categories (e.g., relatives, friends) differed. The items included: (1) “How many relatives do you see or talk to on the phone at least once every 2 weeks?”; (2) “How many friends do you see or talk to on the phone at least once every

2 weeks?”; (3) “How many coworkers do you see or talk to on the phone at least once every 2 weeks?”; and (4) How many cancer patients or survivors do you see or talk to on the phone at least once every 2 weeks?” Participants who were not currently employed were instructed to skip the item on coworkers.

Procedure

Potentially eligible participants were mailed introductory letters notifying them about the study. Interested patients consented to participate by phone. Consenting patients were mailed a survey to complete at home and a pre-paid, addressed envelope for returning the survey.

Screening Procedure

Potential participants were identified through the Indiana Tumor Registry. A tumor registrar sent a list of potentially eligible patients along with their medical record number (MRN), address, phone number, sex, birthdate, race/ethnicity, date of diagnosis, primary cancer site, and staging information to me in October of 2014. A waiver of HIPAA authorization was obtained in order to review the medical records of patients on the list and confirm their eligibility. Their records were examined for information on: (1) age; (2) primary cancer type; (3) diagnosis date; and (4) receipt of treatment at an Indiana University Health hospital in 2013 or 2014. I also searched online obituaries for patients whom I suspected were deceased (e.g., did not attend scheduled appointments, were said to have a poor prognosis), as the medical records were not always accurate regarding vital status.

Recruitment Procedures

I aimed to receive survey data from 140 cancer patients. Based on prior research with a similar recruitment strategy and population (Eakin & Strycker, 2001), I estimated a conservative 60% consent rate and a survey return rate of 70% among consenting participants. Thus, I expected to mail approximately 334 introductory letters in order to consent 200 participants and obtain 140 completed surveys. However, consent and return rates were initially below expectations, based on examination early in the recruitment process. Therefore, I sent introductory letters in weekly batches of 10 to 40 letters until I approached my minimum recruitment goal. To ensure representation of demographic subgroups, I used purposive sampling based on gender and race. I randomly selected potential participants to contact from the Indiana Tumor Registry list, while allowing for approximately equal numbers of men and women. In addition, approximately 68% of the participants selected were Caucasian and approximately 32% were minorities, which is similar to the demographics of Marion County in 2013 (U.S. Census Bureau, 2015).

The introductory letter was sent to notify each potentially eligible person about the study (see Appendix I for introductory mailings). A Study Information Sheet (i.e., consent form without a signature line) and authorization form were also included in the initial mailing with the introductory letter. Any interested person was invited to call for more details. The letter also had an "opt out" component; thus, patients who were not interested in the study could call the undergraduate research assistant (RA) or me to indicate that they did not wish to be contacted further.

The RA or I called all prospective participants who did not opt out approximately five days after the letter was placed in the mail. We described the study, reviewed the

Study Information Sheet and authorization form, and asked if they would like to participate (see Appendix J for telephone script). During that initial call, interested patients provided verbal consent for study participation and verbal authorization to collect information from their medical records. Verbal consent was chosen in place of written informed consent to minimize the number of documents that linked the participant with the research and therefore reduce the risk of a breach of confidentiality. If the patient needed more time or wanted more information, a subsequent phone appointment was scheduled. If requested, a new Study Information Sheet and authorization form were either mailed or emailed to them (based on their preference). Verbal consent was documented by the consenter (see Appendix K for Informed Consent Process Documentation form). If a potential participant did not answer the phone, a brief voicemail was left once (see Appendix J for telephone script), and we called again up to 15 times within approximately 1 to 3 weeks after the first phone call without leaving additional voicemail messages. We searched online obituaries for all patients whom we could not contact to see whether they were deceased.

For patients who declined participation, we asked if they would be willing to provide a reason for their decision. With the patient’s permission, we also documented their age, gender, and race for the purpose of determining potential sample selection biases. When non-participants declined to answer these questions, we discontinued all further contact with them.

Survey Administration and Follow-up Procedures

Participants were mailed a paper survey to complete in the privacy of their homes. Participants were also mailed a letter with instructions for completing the survey (see Appendix L for the survey mailings) and a pre-paid envelope for returning the survey. The survey was pre-marked with the participant’s study ID number, and he or she was instructed to not include any identifiable information (e.g., name, address) on the survey or return envelope. The survey took about 10 to 20 minutes to complete and assessed demographic variables, depressive and anxiety symptoms, somatic symptoms (i.e., sleep disturbance, pain, fatigue), quality of life, general and cancer-related loneliness, negative social expectations, emotional support, social constraints, and social network qualities (see Appendix L for survey mailings). If the questionnaire was not received within approximately 2 weeks, one to 15 (typically three) reminder calls were made as deemed necessary. When we received the survey, the participant was mailed a $25 Target gift card for participating in the study. Replacement surveys were mailed to participants as necessary.

Data Storage and Data Entry

An RA entered and checked all data and I also checked the data entry for every survey. Paper questionnaires and informed consent process documentation forms were stored in a locked filing cabinet in a lockable office in LD 134.

Analyses

Data Screening and Preliminary Analyses

The data were examined for normality, linearity, outliers, and missingness. First, I examined the assumptions of normality and linearity. According to Kline's (2011) guidelines, the values for each study variable were appropriate, except for the open-ended social network size items that had some extreme skew and kurtosis values (discussed subsequently). Second, I examined whether data were missing completely at random using Little's Missing Completely at Random (MCAR) test (Little, 1988). Because my data were shown to be missing completely at random, χ^2 (2278) = 2286.8, p =0.44, and I had very little missingness (i.e., most variables were missing 0.5% of their values), I used imputation to address most missing values. Specifically, when an individual item was missing from a scale, I imputed the value of the strongest correlated item in that scale. Single imputation methods, such as the one used, are considered acceptable when few data are missing and the data are thought to be MCAR (Greenland & Finkle, 1995). When most or all of the items in a scale were missing (e.g., the participant skipped a page or measure), I left the values as missing. The main study analyses were conducted in Mplus statistical software (Muthén & Muthén, 2010), which allowed for the use of full information maximum likelihood (FIML) data imputation to handle the remaining missing values. FIML generates implied values for missing values based on data patterns (Enders, 2001a, 2001b). This strategy allows retention of the original sample size and results in more accurate parameter estimates than deletion methods and single-imputation methods (Enders, 2001a).

Third, data were examined for outliers. Outliers were defined as values greater than 3 standard deviations from the mean. For measures with specified response ranges (i.e., Likert-type scaled measures used for the majority of study variables), all values were retained because extreme values were thought to represent true variability. Some researchers contend that retaining legitimate outliers results in data that are more representative of the true population (Orr, Sackett, & Dubois, 1991). I used a winsorization transformation for outliers on variables without a specified range of responses (i.e., the open-ended social network size questions) (Tukey, 1962). After the winsorization transformation was applied, all skew and kurtosis values were within the acceptable range (i.e., $-3 < \text{skewness} < +3$, $-7 < \text{kurtosis} < +7$) (Kline, 2011). Analyses including the open-ended social network size items were completed twice: once without the winsorization transformation for outliers and once with the winsorization transformation. Both sets of results are included in the results table because they differed substantially, but the winsorized results are discussed subsequently in the text.

Finally, descriptive statistics (e.g., means, standard deviations) were calculated to characterize the sample. T-scores were also calculated for the PROMIS measures for which cancer patient norms were available (i.e., depression, anxiety, pain, fatigue) using the online PROMIS scoring service (see www.nihpromis.org for details).

Assessment of Item Performance

The first step for accomplishing aims 3 and 4 was to assess item quality and eliminate items that performed poorly. I examined the full range of response categories for each item using histograms, means, and standard deviations. In addition, I examined factor loadings, item-total correlations, and inter-item correlations. Items could be removed at any stage of the project based on performance. For example, items could be removed for floor or ceiling effects (i.e., more than 80% endorsed the highest or lowest category), low factor loadings (i.e., <0.40), or low item-total correlations (i.e., <0.30) (Monahan, Lane, Hayes, McHorney, & Marrero, 2009; Nunnally & Bernstein, 1994; Sheskin, 2003). Items with similar content were compared and the items with the best performance were retained for the measures.

Primary Analyses for Quantitative Aims 3 and 4

The dimensionalities of the Cancer Loneliness Scale and Cancer-related Negative Social Expectations Scale were assessed using confirmatory factor analyses in Mplus and LISREL 8.8 statistical software. Regarding the dimensionality of the Cancer Loneliness Scale, unidimensionality was hypothesized (hypothesis #3.1) and examined using Mplus. Regarding the dimensionality of the Cancer-related Negative Social Expectations Scale, three models were compared to determine which model best fit the data (exploratory goal #4.1; see Appendix O for the original proposed models). I examined a 5-dimensional model, 4-dimensional model, and unidimensional model. The 5-dimensional model corresponded to the 5 domains identified in the qualitative study discussed previously. The 4-dimensional model was similar to the 5-dimensional model except that domains 2 (expecting a lack of understanding of cancer-related concerns) and 3 (expecting that others will not understand existential thoughts) were collapsed due to conceptual similarity. Specifically, both domains involved expectations that others would not understand their thoughts. All models were initially run in Mplus statistical software;

however, not positive definite errors were obtained from the multidimensional models, yielding invalid parameter estimates. The not positive definite errors were not obtained when the same analyses were performed in LISREL; thus, statistics from LISREL are reported subsequently for the multidimensional models. All models were run using a robust maximum likelihood estimator.

To evaluate the models' fit, I examined a number of fit indices assessing absolute fit, fit adjusting for model parsimony, and comparative fit. Specifically, I examined the standardized root mean square residual (SRMR) statistic to assess absolute fit, the root mean square error of approximation (RMSEA) statistic adjusting for model complexity, and the comparative fit indices (CFI), as suggested by Hu and Bentler (1999). Model fit guidelines vary, but, in general, acceptable model fit is defined as: (1) SRMR$\leq$ 0.08; (2) RMSEA $\leq$ 0.06; and (3) CFI $\geq$ 0.95 (Hu & Bentler, 1999; Kline, 2011).

Reliability and validity analyses were also conducted. Alpha coefficients were obtained from SPSS statistical software to address hypothesis #3.2 and goal #4.2 related to the measures' internal consistency reliabilities. Hypothesis #3.3 and goal #4.3 focus on the construct validity of the Cancer Loneliness Scale and Cancer-related Negative Social Expectations Scale. I assessed validity evidence using correlational analyses in LISREL 8.8 (Joreskog & Sorbom, 2008). LISREL was used for correlational analyses so that remaining missingness could be handled with FIML.

Power Analysis

The target sample size (*N* = 140) was determined based on the original proposed analyses for the project (i.e., one unidimensional confirmatory factor analysis with 15 items and one mediation model). A sample with a minimum of 5 participants per pathway is thought to be required for sufficient power to detect effects based on simulations (Kline, 2011). The original proposed mediation model contained 28 pathways; thus, following Kline’s (2011) guidelines, a sample of 140 was thought to provide sufficient statistical power. Furthermore, a statistical simulation in MPlus indicated that, assuming 15 items and true factor loadings of 0.40, 140 is a sufficient number for the proposed factor analysis (P. Monahan, *personal communication*). Thus, 140 was initially selected as the target sample size.

The actual sample size for the quantitative study was 186, as more patients agreed to participate and returned their surveys than initially anticipated based on examination early in the recruitment process. The number of pathways in the examined models ranged from 8 (i.e., unidimensional Cancer Loneliness Scale model) to 22 (i.e., 5-dimensional Cancer-related Negative Social Expectations Scale), suggesting that the final sample size of 186 provided sufficient statistical power for all models.

QUANTITATIVE STUDY RESULTS

Sample Characteristics

A total of 380 randomly selected patients were deemed eligible based on my medical chart review and were sent introductory letters. Of the 380 patients sent introductory letters, 36 (9%) were discovered to be ineligible based on the phone call. Of the remaining 344 presumably eligible patients, 215 (63%) consented to participate, 47 (14%) declined participation, and 82 (24%) could not be contacted to determine their interest in participating or confirm their eligibility. Of the 215 consenters, 186 (87%) returned their surveys, 1 (0.005%) withdrew from the study, 1 (0.005%) died, and 27 (13%) were lost to follow-up. A detailed study flow chart is found in Figure M1 of Appendix M. Excluding the participant who withdrew from the study (because we did not collect their personal information) and the participant who died, participants who returned their surveys (*n*=186) did not significantly differ from participants who did not return their surveys (*n*=27) on age, gender, treatment type, and cancer stage; however, participants who returned their surveys had a shorter time since diagnosis (*M*= 16.75 months, *SD* = 3.2 months) than those who did not return their surveys (*M*=18.50 months, *SD* = 3.7 months), *t*(212)= -2.6, *p* = .01.

Sample characteristics are shown in Table N2 of Appendix N. Approximately half (51%) of the participants were female and the mean age was 59 years (*SD*=12.6). The majority were Caucasian (74%) and married or living with a partner (68%). Most (59%) had received at least some college education, and 42% were employed either full or part-time. Patients had been diagnosed with a wide variety of cancer types, with the most common being breast (16%), prostate (11%), skin (8%), uterine (7%), and kidney (7%) cancers. The majority (63%) were diagnosed with early-stage disease. The average time since the cancer diagnosis was approximately 17 months (*SD*=3.2). The most common cancer treatments included surgery (83%), chemotherapy (38%), radiation (33%), and hormone therapy (19%).

Descriptive Statistics

Descriptive statistics for study variables are shown in Appendix N, Table N3. On average, patients reported that they "sometimes" received emotional social support (*M*=17.0, *SD*=3.7, range=4.0-20.0). In addition, patients, on average, reported that they "never" felt depressed (*M*=7.1, *SD*=3.5, range=4.0-18.0, t-score = 51.0) or anxious (*M*=7.3, *SD*=3.4, range=4.0-19.0, t-score=51.5), which was comparable to that of a representative sample of American cancer patients (see www.nihpromis.com for details about the calibration sample). Furthermore, on average, patients reported experiencing "a little bit" of pain (*M*=7.8, *SD*=4.5, range=4.0-20.0, t-score=51.7), fatigue (*M*=7.8, *SD*=4.5, range=4.0-20.0, t-score=52.4), and sleep disturbance (*M*=9.9, *SD*=3.9, range=4.0-20.0). Patients' levels of pain and fatigue were also comparable to those of a representative sample of American cancer patients (see www.nihpromis.com for information about the calibration sample). Patients' average level of sleep disturbance was comparable to levels reported in another study of cancer patients (Stachler et al., 2014). Additionally, on average, patients' mental quality life (*M*=14.2, *SD*=3.1, range=6.0-20.0) was similar to levels reported by the general population, whereas their physical quality of life (*M*=12.3, *SD*=2.3, range=6.0-17.0) was slightly greater than levels reported by the general population (Hays et al., 2009). Furthermore, patients reported experiencing low levels of social constraints on average (*M*=9.5, *SD*=4.2, range=5.0-25.0), consistent with prior research with cancer patients (Hoyt, 2009; Mosher et al., 2012). Patients also experienced moderate levels of loneliness on average (*M*=37.0, *SD*=11.3, range=20.0-78.0), consistent with the results of a recent meta-analysis of studies with cancer patients (Deckx et al., 2014). Finally, the average numbers of relatives, friends, coworkers, and other cancer patients that participants reported seeing or talking to on the phone at least once every 2 weeks were 5.9 (*SD* = 4.3; range = 0.0-30.0), 7.9 (*SD* = 11.1; range = 0.0-100.0), 12.4 (*SD* = 13.0; range = 0.0-60.0), and 1.6 (*SD* = 2.5; range = 0.0-25.0), respectively.

Cancer Loneliness Scale Item Selection, Factor Structure, and Reliability

First, I selected the items for the Cancer Loneliness Scale. All of the items from the item pool performed well (e.g., all response categories were endorsed, all had adequate item-total correlations) (see Appendix P, Table P4 for item descriptive statistics and Table P5 for inter-item correlations). Thus, no items were eliminated due to poor performance. Next, Dr. Mosher and I grouped the items with content overlap and selected one representative item from each group with the highest item-total correlation (see Appendix P, Table P6 for the item groups and selected items). A total of 7 items were retained for the final measure.

After the items were selected, I examined the hypothesized unidimensional factor structure of the Cancer Loneliness Scale (hypothesis #3.1). Figure P6 in Appendix P shows the final model. Overall, the final model showed adequate fit as determined by the goodness of fit indices (i.e., SRMR=0.02; RMSEA=0.09; CFI=0.98; $\chi^2(14)=36.75$, $p=0.0001$). Values for the SRMR and CFI indicated good absolute fit and comparative fit, respectively. However, the RMSEA, assessing parsimony, did not fall within the range of values recommended by Hu and Bentler (1999) (i.e., RMSEA $\leq$ 0.06). Of note, other statisticians have suggested that values closer to the value observed in this study (i.e., $\leq$ 0.08) might indicate adequate fit (Brown, 2006). Because the overall model fit was judged to be adequate, I examined whether the internal consistency coefficient of the single-factor scale was greater than 0.70 (hypothesis #3.2). As hypothesized, internal consistency reliability for the Cancer Loneliness Scale was excellent ($\alpha=0.94$).

Cancer Loneliness Scale Construct Validity

To assess the construct validity of the Cancer Loneliness Scale (hypothesis #3.3), I examined theoretical relationships between cancer-related loneliness and a number of social and health characteristics. Zero-order correlations appear in Table P12 of Appendix P. First, as hypothesized (hypothesis #3.3a), cancer-related loneliness was positively correlated with general loneliness ($r=0.67$, $p<0.0001$), social constraints ($r=0.80$, $p<0.0001$), anxiety symptoms ($r=0.55$, $p<0.0001$), depressive symptoms ($r=0.54$, $p<0.0001$), sleep disturbance ($r=0.51$, $p<0.0001$), pain ($r=0.50$, $p<0.0001$), and fatigue (r=0.45, p<0.0001). Second, as hypothesized (hypothesis #3.3b), cancer-related loneliness was negatively correlated with mental quality of life (r=-0.54, p<0.0001), physical quality of life (r=-0.33, p=0.001), and emotional support (r=-0.66, p<0.0001); however, contrary to my hypothesis, cancer-related loneliness was not correlated with the number of cancer patients with whom participants had spoken via phone or seen at least once every 2 weeks when the winsorization transformation was applied (r=-0.14, p=0.06). Finally, as hypothesized (hypothesis #3.3c), cancer-related loneliness was unrelated to the number of coworkers with whom participants had contact at least once every 2 weeks after the winsorization transformation was applied (r=-0.14, p=0.06); however, contrary to my hypothesis, cancer-related loneliness was positively correlated with the number of relatives (r=0.41, p<0.0001) and friends (r=0.44, p<0.0001) with whom participants had contact at least once every 2 weeks.

Cancer-Related Negative Social Expectations Scale Item Selection, Factor Structure, and Reliability

First, I examined the performance of potential items for the Cancer-related Negative Social Expectations Scale (see Appendix P, Table P9 for the item descriptive statistics and Table P8 for inter-item correlations). Items 5 and 11 had particularly low inter-item correlations (i.e., many *ps*>0.05) and low item-total correlations (i.e., 0.16 and 0.29, respectively); thus, I opted to remove those items from the pool. The other items appeared to perform well and were initially retained.

Next, I examined the three contending factor structure models (goal #4.1). The resulting models are shown in Figures P7-9 of Appendix P. Regarding the 5-dimensional model, the model fit was adequate as determined by goodness of fit indices (i.e., SRMR=0.06; RMSEA=0.07; CFI=0.99; $\chi^2(47)=92.68$, $p<0.001$). Values for the SRMR and CFI indicated good absolute fit and comparative fit, respectively. However, similar to the Cancer Loneliness Scale model, the RMSEA, assessing parsimony, did not fall within the range of values recommended by Hu and Bentler (1999) (i.e., RMSEA $\leq$ 0.06). Furthermore, there were high correlations among some of the factors (see Appendix P, Table P9), with some invalid values above one. High correlations suggested that the factors were not separate. Similar to the 5-dimensional model, the 4-dimensional model showed adequate fit as determined by goodness of fit indices (i.e., SRMR=0.04; RMSEA=0.07; CFI=0.99; $\chi^2(49)=92.10$, $p<0.001$). Again, the values for the SRMR and CFI indicated good fit, whereas the RMSEA fell slightly above the recommended range of values. High correlations between the 4 factors (e.g., 0.99, see Figure P8) again were problematic and suggested that the factors were not separate. Finally, I examined the unidimensional factor structure model. Figure P9 of Appendix P displays the factor loadings. Goodness of fit indices suggested that the unidimensional model had adequate absolute fit (SRMR=0.04), but was inadequate in regards to parsimony (RMSEA=0.09) and comparative fit (CFI=0.94). The chi-square was significant ($\chi^2(54)=130.30$, $p<0.001$). The values for these fit indices fell just outside of the range of values recommended by Hu and Bentler (1999). A comparison of the model fit indices for all examined models is shown in Table P10 of Appendix P. After reviewing the three models, I decided to reject the 5- and 4-dimensional models because the correlations between the factors were too high and sometimes invalid (i.e., greater than one). I also decided to not combine any subsets of the factors with high correlations because I had no theoretical rationale for doing so. Thus, I decided to retain the unidimensional model as the best representation of my data.

Next, I shortened the measure to increase its practicality for cancer populations. I decided to retain one item from each conceptual domain for representative content coverage; the item with the highest item-total correlation was retained (see Appendix P, Table P11 for the final list of items retained). After shortening the measure to five items, I re-ran the unidimensional model with the final five items (see Appendix P, Figure P10). The resulting model showed adequate fit overall as determined by the goodness of fit indices (i.e., SRMR=0.02; RMSEA=0.11; CFI=0.98; $\chi^2(5)=15.37$, $p=0.01$). The absolute fit (SRMR) for this model was superior to that of all other models examined, whereas the adjustment for model complexity (RMSEA) was worse than that of all other models and the comparative fit (CFI) was better than that of the longer unidimensional measure model. Overall, the SRMR and CFI fell within the recommended ranges of values, whereas the RMSEA fell outside of the recommended range. The overall model fit was deemed to be adequate; thus, I examined the internal consistency coefficient for the single-factor scale (goal #4.2), which was excellent ($\alpha=0.90$).

Cancer-related Negative Social Expectations Scale Construct Validity

To assess the construct validity of the Cancer-related Negative Social Expectations Scale (goal #4.3), I examined theoretical relationships between cancer-related loneliness and a number of social and health characteristics. Zero-order correlations appear in Table P12 of Appendix P. First, as expected (goal #4.3a), negative social expectations were positively correlated with general loneliness ($r=0.47$, $p<0.0001$), cancer-related loneliness (*r*=0.70, *p*<0.0001), social constraints (*r*=0.67, *p*<0.0001), anxiety symptoms (*r*=0.41, *p*<0.0001), depressive symptoms (*r*=0.41, *p*<0.0001), sleep disturbance (*r*=0.43, *p*<0.0001), pain (*r*=0.36, *p*<0.0001), and fatigue (*r*=0.39, *p*<0.0001). Second, as expected (goal #4.3b), negative social expectations were negatively correlated with mental quality of life (*r*=-0.43, *p*<0.0001), physical quality of life (*r*=-0.31, *p*=0.001), and emotional support (*r*=-0.48, *p*<0.0001).

QUANTITATIVE STUDY DISCUSSION

The current study aimed to develop and evaluate the psychometric properties of measures of cancer-related loneliness and cancer-related negative social expectations. The final products of the project included a 7-item unidimensional Cancer Loneliness Scale and 5-item unidimensional Cancer-related Negative Social Expectations Scale. Excellent evidence for reliability and validity was found for both measures using a large, diverse sample of cancer patients. The resulting measures have both clinical and research utility.

Cancer Loneliness Scale

Excellent evidence for reliability and validity was found for the Cancer Loneliness Scale. As expected, the measure was found to be unidimensional and to have excellent internal consistency. Furthermore, the measure was associated with measures of mental and physical health theoretically linked to cancer-related loneliness, which provided evidence of construct validity. First, as hypothesized, cancer-related loneliness was positively correlated with general loneliness. The moderately strong relationship between general and cancer-related loneliness is expected because both constructs involve dissatisfaction with relationships and, thus, the general loneliness measure should capture some loneliness attributed to cancer. Additionally, cancer-related loneliness was positively correlated with anxiety and depressive symptoms and negatively correlated with mental quality of life. These findings are consistent with prior theory and research linking general loneliness with poor mental health outcomes in cancer patients and other populations (Cacioppo & Hawkley, 2009; Cacioppo et al., 2006; Hawkley & Cacioppo, 2003; Jaremka, Andridge, et al., 2014; Pehlivan et al., 2012; Peplau & Perlman, 1982). Furthermore, cancer-related loneliness was positively correlated with pain, fatigue, and sleep disturbance and negatively correlated with physical quality of life. Again, these findings are consistent with theory and prior research linking general loneliness to poor physical health-related outcomes in cancer patients and the general population (Cacioppo & Hawkley, 2009; Cacioppo, Hawkley, Crawford, et al., 2002; Hawkley & Cacioppo, 2003; Jaremka, Andridge, et al., 2014; Pehlivan et al., 2012). Loneliness is hypothesized to negatively impact both physical and mental health outcomes through mechanisms such as reduced immune functioning, sleep disturbance, and poor health behaviors (Cacioppo, Hawkley, Crawford, et al., 2002).

Construct validity was also assessed by examining theory-driven relationships between cancer-related loneliness and measures of social network qualities. First, cancer-related loneliness was positively correlated with social constraints and negatively correlated with emotional support, consistent with social cognitive processing theory and prior literature (Deckx et al., 2014; Lepore, 2001; Mosher et al., 2012; Sahin & Tan, 2012; Yildirim & Kocabiyik, 2010). Specifically, according to social cognitive processing theory, a socially constraining environment impedes psychological adjustment (i.e., increases loneliness) by preventing successful cognitive and emotional processing of cancer-related information, whereas a supportive social environment facilitates the processing of stressor-related information and promotes adjustment (Lepore, 2001). In addition, the positive relationship between social constraints and cancer-related loneliness was strong (*r*=0.80). There is a lack of consensus in the literature regarding the strength of correlations indicating redundancy between constructs, though some statisticians have suggested correlations of 0.90 and higher indicate redundancy (Tabachnick & Fidell, 2001). The strong correlation between social constraints and cancer-related loneliness is consistent with social cognitive processing theory; thus, the high correlation provides appropriate evidence of construct validity.

Regarding more objective social network qualities, I hypothesized that cancer-related loneliness would be negatively related to the number of cancer patient contacts and unrelated to the number of friend, relative, and coworker contacts based on loneliness theory and prior literature (Egestad, 2013; Peplau & Perlman, 1982; Russell et al., 1980). Specifically, loneliness theory suggests loneliness is not a result of actual isolation or one's number of social network members, but instead relates to dissatisfaction with relationships (Peplau & Perlman, 1982; Russell et al., 1980); however, in qualitative research, cancer patients have reported that having more contact with other cancer patients reduced their feelings of loneliness (Egestad, 2013). Overall, results regarding objective social network characteristics were not consistent with my predictions. For example, cancer-related loneliness was not associated with the number of cancer patients with whom patients reported communicating regularly. This result suggests that, consistent with theory regarding non-patients (Peplau & Perlman, 1982; Russell, 1996), the quality of the interaction may be more important than the quantity. Particularly, contact with other cancer patients may be a positive or negative experience depending on a number of factors, such as how well they feel understood by the other patient. For instance, interacting with a patient with very disparate experiences (e.g., better prognosis, fewer symptoms, different type of treatment) may heighten feelings of misunderstanding and loneliness. Conversely, a conversation with a patient with similar cancer-related experiences and perceptions may be a particularly positive social experience that reduces feelings of loneliness. Thus, the potential for both negative and positive social exchanges with other patients provides a possible explanation for the null effect.

Also contrary to my hypotheses, the number of friends and relatives with whom participants had contact at least once every 2 weeks was positively correlated with cancer-related loneliness. In the general loneliness literature, findings are mixed regarding relationships between loneliness and more objective social network characteristics (e.g., amount of time spent with others, size of social network), with some studies reporting significant associations (Freberg, Adams, McGaughey, & Freberg, 2010; Green, Richardson, Lago, & Schatten-Jones, 2001; Russell, 1996) and others reporting null findings (Peplau & Perlman, 1982; Russell, 1996). The reasons for these mixed findings are unclear and should be studied in future research. The present study findings differed from those of existing studies reporting a significant relationship between general loneliness and number of social contacts (Freberg et al., 2010; Russell, 1996) in that having more friend and relative contacts was associated with greater cancer-related loneliness. One potential explanation is that having more contact with others provided more opportunities to experience socially constraining behaviors or feel misunderstood with respect to the cancer experience, which led to greater loneliness.

Finally, consistent with my prediction, cancer-related loneliness was unrelated to the number of coworkers with whom participants had contact at least once every 2 weeks. Although this finding is consistent with loneliness theory (Peplau & Perlman, 1982; Russell, 1996), it is inconsistent with the results regarding contact with friends and relatives. This inconsistency in findings might be related to a number of factors. First, patients may have different expectations for relationships with coworkers than friends and relatives (e.g., may not expect the same level of understanding and therefore may have fewer opportunities to be disappointed). Second, the number of coworkers might be confounded with other variables, such as job type (e.g., jobs involving direct service provision vs. technical labor with limited social interaction), which may be directly or indirectly associated with cancer-related loneliness.

Alternate explanations for the inconsistent social network variable findings should be considered. Of note, although most of the items assessing social contact in this study have been used in prior research (Cohen et al., 1997; Ellwardt, van Tilburg, Aartsen, Wittek, & Steverink, 2015), reliability or validity evidence for these items has not been published. Thus, another possible explanation for the findings is measurement error. For example, patients may have had poor recall for the number of people with whom they interacted over the past 2 weeks. Additionally, patients may have interpreted the questions differently (e.g., with some only reporting the number of people with whom they interacted frequently or had more substantial conversations and others reporting the number of people with whom they had any form of contact), leading to inconsistency in reporting. Notably, results were dramatically different when the winsorization transformation was applied, even though few values were changed (2 values for number of cancer patient contacts, 5 values for number of friend contacts, 5 values for number of relative contacts, and 1 value for number of coworker contacts). For the number of cancer patient, friend, and relative contacts, the direction of the relationship changed when the winsorization transformation was applied. For the number of cancer patient, relative, and coworker contacts, the presence of statistical significance changed. In some cases the winsorization transformation made the results more consistent with my predictions, whereas in other cases it made the results less consistent with my predictions. As discussed in the methods section, several skew and kurtosis values on the social network variables were outside the acceptable range before I applied the winsorization transformation, providing a rationale for interpreting the winsorized values. Overall, the ambiguous results might reflect both measurement error and the ambiguous nature of the relationship between quantity of social contact and loneliness. Namely, theory suggests that people have different social needs and expectations and that a discrepancy between what they want and have is associated with their relationship satisfaction (Peplau & Perlman, 1982). Thus, to some extent, both the quantity and quality of social contacts affect loneliness, but these relationships are likely to differ across individuals. These associations are further complicated by the fact that social contact may include both positive and negative interactions; at times a patient may feel misunderstood even by their most trusted confidant. Therefore, the relationships between social network qualities and loneliness are complex and challenging to examine.

Overall, evidence for the construct validity of the Cancer Loneliness Scale was deemed to be good, as the majority of theoretical relationships were found.

Cancer-related Negative Social Expectations Scale

Excellent evidence for reliability and validity also was found for the Cancer-related Negative Social Expectations Scale. Three factor structures were examined and the unidimensional model exhibited the best fit and was retained. Results may indicate that patients often endorse a single underlying pattern of thinking about relationships rather than a tendency to have different types of social expectations for different social situations. Additionally, the high internal consistency for the unidimensional measure in this study provides evidence for reliability.

The Cancer-related Negative Social Expectations Scale was associated with measures of health and social well-being theoretically linked to negative social expectations, which provides evidence of construct validity. First, as hypothesized, cancer-related negative social expectations were positively correlated with both general and cancer-related loneliness. To my knowledge, this is the first empirical test of the relationship between negative social expectations and loneliness in any population, providing support for theory suggesting negative social cognitions precipitate and sustain loneliness (Cacioppo & Hawkley, 2009). The correlation (r=0.70) between negative social expectations and cancer-related loneliness was stronger than the correlation (r=0.47) between negative social expectations and general loneliness, which is expected because the negative social expectations and cancer-related loneliness measures both focus on cancer-specific experiences. As discussed previously, high correlations (such as between negative social expectations and cancer-related loneliness) are not necessarily indicative of construct redundancy. Again, there is a lack of consensus in the literature regarding the strength of correlations indicating redundancy, though some statisticians have suggested correlations of 0.90 and higher might indicate redundancy (Tabachnick & Fidell, 2001). The strong correlation between negative social expectations and cancer-related loneliness is consistent with theory (Cacioppo & Hawkley, 2009) and, thus, the high correlation provides appropriate evidence of construct validity.

Second, the positive relationships between negative social expectations and anxiety and depressive symptoms are consistent with cognitive theory suggesting negative thought patterns underlie anxiety and depressive disorders (A. Beck, 1970; Clark & Beck, 1989). Specifically, cognitive theory posits that thoughts and feelings are linked; unhelpful thoughts are hypothesized to increase distress (A. Beck, 1970; Clark & Beck, 1989). Third, negative social expectations were positively associated with pain, fatigue, and sleep disturbance and negatively associated with quality of life, supporting theory suggesting negative social expectations impact health outcomes (Cacioppo & Hawkley, 2009). Specifically, negative social expectations are hypothesized to negatively affect health outcomes by increasing loneliness, which is associated with a number of health risk factors (e.g., HPA axis dysfunction, sleep disturbance, inflammation) (Cacioppo & Hawkley, 2009; Cacioppo, Hawkley, Crawford, et al., 2002). Finally, negative social expectations were positively correlated with social constraints and negatively correlated with emotional support, consistent with theory positing that negative social expectations increase social behaviors that elicit negative social interactions (Cacioppo & Hawkley, 2009). Thus, overall, results were consistent with my predictions and provided excellent evidence of construct validity.

Limitations and Future Directions

Limitations of this study include potential response bias and measurement error. Although my consent and survey return rates were comparable to similar telephone and mail-based survey research (Eakin & Strycker, 2001), only 54% of the 344 presumably eligible patients returned their surveys. It is possible that patients who participated differed from those who chose not to participate or could not be contacted. For instance, non-participants often reported feeling too ill or distressed to participate; thus, study participants may have had fewer symptoms than non-participants. Future studies could reduce response bias by employing alternate recruitment techniques (e.g., clinic-based recruitment) that tend to yield higher response rates. Furthermore, participants completed the surveys at home and may not have completed them independently, although they were instructed to do so. Responding in a socially desirable manner is always a concern using self-report methods, but may be of particular concern if patients' family members assist them with completing questions about social functioning. For example, a patient might report greater satisfaction with relationships (e.g., less loneliness, greater social support, fewer social constraints) if a family member is present. Participation in private offices could reduce this potential bias in future studies. Additionally, construct validity was determined via correlations with self-report measures, which are subject to a number of biases. For instance, items regarding number of contacts could be self-reported incorrectly due to social desirability or forgetfulness. Thus, use of more objective measures (e.g., clinician ratings of video-recorded social exchanges) to assess construct validity in future studies may provide more accurate results.

Other limitations related to measure development also should be noted. First, I was unable to obtain qualitative feedback on the items assessing negative social expectations prior to administration. Receiving patient and further expert feedback may have led to increased clarity in item wording and prevented the administration of confusing items. For example, two items were immediately eliminated for poor performance. After closer examination, it appeared that the items could have been interpreted in multiple ways, which likely led to the low item-total correlations. Second, I was unable to assess test-retest reliability because a longitudinal study was not feasible for this project. Thus, examination of the measures' test-retest reliability is an important direction for future research. Furthermore, results of this study provide only preliminary evidence of the measures' psychometric properties. The current analyses should be conducted using a larger, more representative sample. Inclusion of diverse populations would allow the assessment of measurement invariance across racial or ethnic groups. Additionally, participant burden concerns prevented me from measuring associations between the new measures and many other constructs (e.g., stigma, protective buffering, social skills, social anxiety, other types of negative expectations) that should be examined in future work. Finally, examining whether cancer-related negative social expectations predict cancer-related loneliness over time would provide a more rigorous test of the theory (Cacioppo & Hawkley, 2009), as well as a better indication of whether cognitive-based interventions should be tested to reduce loneliness in cancer patients.

Implications

The current project has a number of implications for theory, clinical practice, and clinical research. First, to my knowledge, this is the first study to develop and evaluate measures of cancer-related loneliness and negative social expectations for any population. Thus, this study provided the first empirical test of the theoretical relationship between negative social expectations and loneliness in any population, and results were consistent with loneliness theory (Cacioppo & Hawkley, 2009). Additionally, this study expands on existing theory by examining these concepts in cancer patients, a population that may be at high risk of developing loneliness (Deckx et al., 2014; Wells & Kelly, 2008). In particular, I identified specific cancer-related negative social expectations and found a positive association between these expectations and loneliness attributed to cancer. Furthermore, this study provides an initial test of aspects of loneliness theory by linking negative social expectations to mental and physical health outcomes (i.e., depressive and anxiety symptoms, somatic symptoms, quality of life). Loneliness theory suggests negative social expectations increase loneliness, which in turn negatively impacts health (Cacioppo & Hawkley, 2009).

The project also has a number of clinical implications and applications. First, the Cancer Loneliness Scale has utility for assessing loneliness in clinical settings. Loneliness is a known risk factor for poor physical, emotional, and social outcomes in general and cancer populations (Cacioppo & Hawkley, 2009; Cacioppo et al., 2006; Drageset et al., 2013; Hawkley & Cacioppo, 2003; Jaremka, Fagundes, Glaser, et al., 2013; Jaremka, Fagundes, Peng, et al., 2013), and in this study I found that cancer-related loneliness also is associated with a variety of poor outcomes. Thus, screening for loneliness may aid the identification of patients that may benefit from a referral to mental health treatment. For instance, the Cancer Loneliness Scale could be used to identify patients who may warrant a cancer-specific loneliness intervention. Distress screening has become more commonplace in cancer centers in recent years, with many researchers and clinicians recommending that distress screening be incorporated into standard guidelines (Carlson & Bultz, 2003; Holland & Bultz, 2007). Indeed, implementation of distress screening into standard practice has shown promise for enhancing patient-provider communication regarding mental health (Taenzer et al., 2000; Velikova, Brown, Smith, & Selby, 2002). Additionally, the Cancer Loneliness Scale could be used to assess whether an intervention reduced cancer-related loneliness. Furthermore, if the current findings are replicated longitudinally, this would suggest that targeting negative social expectations in loneliness interventions might be beneficial. Therapists could select negative social cognitions upon which to intervene based on item responses to the Cancer-related Negative Social Expectations Scale. Following the intervention, researchers could use the measure to empirically evaluate whether reduced negative social expectations mediated the beneficial effects of a cognitive intervention on cancer patients' loneliness.

Conclusions

Loneliness is associated with poor mental and physical health outcomes in cancer patients (Drageset et al., 2013; Jaremka, Fagundes, Glaser, et al., 2013; Jaremka, Fagundes, Peng, et al., 2013; Jaremka, Peng, et al., 2014). Cancer patients may experience loneliness specifically related to the cancer experience; thus, loneliness interventions in cancer should be tailored to address illness-related social conditions and negative social expectations. In the current project I developed two cancer-specific tools for use in future theory-based loneliness research. Development of theory-based loneliness reduction interventions may be critical to improving cancer patients’ mental and physical health outcomes.

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APPENDICES

Appendix A. Handout with Cancer Loneliness Scale

The following statements describe how people sometimes feel after being diagnosed with cancer. For each statement, please indicate how often you have felt that way by writing a number in the space provided.

NEVER	RARELY	SOMETIMES	OFTEN	ALWAYS
1	2	3	4	5

1. Since your cancer diagnosis, how often have you felt that people are around you but not with you? ______

2. How often do you feel left out because of your cancer? ______

3. Since your cancer diagnosis, how often have you felt that you were not important to others? ______

4. How often do you feel that there is no one you can share the ups and downs of cancer with? ______

5. How often does having cancer make you feel empty? ______

6. Since your cancer diagnosis, how often have you felt misunderstood even by your closest friends and family members? ______

7. How often do you feel that others cannot provide the support you need to deal with your cancer? ______

8. Since your cancer diagnosis, how often have you felt that you don’t have a lot in common with the people around you? ______

9. How often do you feel that you cannot share personal thoughts about cancer with anyone? ______

10. Since your cancer diagnosis, how often have you felt that you were not needed by others? ______

11. How often does having cancer make you feel alone? ______

12. How often do you feel that no one really understands how cancer has affected you? ______

13. Since your cancer diagnosis, how often have you experienced a general sense of emptiness? ______

14. How often does your cancer diagnosis make you feel isolated from others? ______

15. Since your cancer diagnosis, how often have you felt that you are no longer close to anyone? ______

Please circle questions that:

- **Don’t make sense**
- **Aren’t clear enough**
- **Are missing something**
- **Have any other problem**

Thank you for your time!

Appendix B. Screening Form for Qualitative Study

Indiana University Simon Cancer Center
Development of Loneliness Questionnaires for Cancer Patients

Date: ______/______/______

Patient's Name: __________________

MRN:____________________

Eligibility Screening: Record Review and Physician Contact	**Yes**	**No**
1) Person who was diagnosed with cancer and is receiving care at IUSCC?		
2) Person who is undergoing active treatment for cancer?		
2) 18 years of age or older?		
3) Attending physician contacted and confirmed eligibility? ☐ Attending: ☐ Date of confirmation:		

☐ **Patient agreed to participate:**

Consent Date: ___/____/___

☐ **Patient declined participation: (please check ALL that apply)**

(1) ___ Not interested
(2) ___ Not feeling well or has other health reasons
(3) ___ No time
(4) ___ Study participation is too much work/Too difficult
(5) ___ Other, specify: ___________________________

Patient Age:_____

Patient Gender:____

Appendix C. Consent Form for Qualitative Study

INDIANA UNIVERSITY INFORMED CONSENT STATEMENT FOR

Development of a Loneliness Questionnaire for Cancer Patients

You are invited to participate in a research study about the social experiences of cancer patients. You were selected as a possible subject because you have been diagnosed with cancer. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

The study is being conducted by Dr. Catherine Mosher, Assistant Professor of Psychology at the IUPUI School of Science. It is funded by the National Cancer Institute and the Psychology Department at IUPUI.

STUDY PURPOSE

The purpose of this study is to learn about cancer patients' social experiences. We also want to get feedback on a questionnaire about loneliness so that we can improve it.

NUMBER OF PEOPLE TAKING PART IN THE STUDY:

If you agree to participate, you will be one of 30 subjects who will be participating in this research.

PROCEDURES FOR THE STUDY:

If you agree to be in the study, you will do the following things:

If you choose to take part in this study, we will give you a paper survey to fill out in the clinic. It will take about 5 to 8 minutes. The survey includes questions about you. These include:

- Your education and employment
- Your mood
- Your relationships
- Your experience coping with cancer

After you take the survey, you will have a private interview in the clinic with a researcher. It will take about 10 to 30 minutes. First, you will answer questions about your social experiences as a cancer patient. Next, you will be asked to provide feedback on a questionnaire about loneliness.

With your permission, we will audiotape your interview. Each tape will have a code number to protect your confidentiality. You may ask to turn the tape off at any time.

If you choose to take part in this study, we will collect the following information from your medical record:

- Age
- Gender
- The date you were diagnosed with cancer
- The type of cancer you were diagnosed with
- The stage of the cancer
- Your treatments for cancer (surgery, radiation, chemotherapy, or other treatments)

RISKS OF TAKING PART IN THE STUDY:

While on the study, there is a risk that you will feel uncomfortable with some of the questions. You may skip any of the questions. Another risk of taking part in the study is that you may experience some distress, including anxiety, sadness, or negative thoughts. If you do experience distress, then you may contact the study investigator and psychologist, Dr. Catherine Mosher (phone: 317-274-6769). You may also contact Dr. Mosher with any questions or concerns about the study.

There is also a risk of possible loss of confidentiality. We will protect your information to the limit of the law. We will keep your information in passphrase protected electronic files or in lockable file cabinets in a private office. When the study ends, we will remove all identifying information from study data and materials. There is also a risk of loss of confidentiality since members of our research team will know you and the information you share. Your information will be kept confidential and only members of the research team will have access to your records. Unless law requires us, we will not share that information with anyone.

BENEFITS OF TAKING PART IN THE STUDY:

You may not benefit directly from this study. Your taking part in this study may benefit other cancer patients in the future.

ALTERNATIVES TO TAKING PART IN THE STUDY:

You do not have to participate in this study if you do not want to. If you choose not to participate, you will receive the same care from your doctor.

CONFIDENTIALITY

Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Your identity will be held in confidence in reports in which the study may be published. Only the research team will have access to the tape recordings. These recordings will be destroyed at the end of the study.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the study investigator and her research associates, the Indiana University Institutional Review Board or its designees, the study sponsor, the IUPUI Psychology Department, and (as allowed by law) state or federal agencies, specifically the Office for Human Research Protections (OHRP), the National Cancer Institute (NCI), the National Institutes of Health (NIH), etc., who may need to access your medical and and/or research records.

COSTS

There are no costs to participate in this study.

PAYMENT

You will receive payment for taking part in this study. After you have completed the survey and interview, you will be handed a $25 Target gift card.

CONTACTS FOR QUESTIONS OR PROBLEMS

For questions about the study or a research-related injury, contact the researcher Dr. Catherine Mosher at 317-274-6769. If you cannot reach the researcher during regular business hours (i.e.

8:00AM-5:00PM), please call the IU Human Subjects Office at (317) 278-3458 or (800) 696-2949.

For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IU Human Subjects Office at (317) 278-3458 or (800) 696-2949.

VOLUNTARY NATURE OF STUDY

Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. Your decision whether or not to participate in this study will not affect your current or future relations with Indiana University Simon Cancer Center.

Your participation may be terminated by the investigator without regard to your consent in the following circumstances: If the investigator feels it is in the best interest of your health and welfare.

SUBJECT'S CONSENT

In consideration of all of the above, I give my consent to participate in this research study.

I will be given a copy of this informed consent document to keep for my records. I agree to take part in this study.

Subject's Printed Name:____

Subject's Signature:____**Date**:
(must be dated by the subject)

Signature of Person Obtaining Consent:____________________________________**Date**:

Appendix D. Medical Record Data Collection Form for Qualitative Study

Medical Record Information:

Patient's Demographics:

(1) Age: _____

(2) Gender ☐ Male ☐ Female

Patient's Cancer History:

(1) Cancer Type(s): ___________________

(2) Date(s) of Diagnosis: ____/____/_____

(3) Disease Stage(s) (i.e., early vs. late stage) : _________________

Treatments for Cancer (**check all that have been received)**:

☐ Surgery
☐ Chemotherapy
☐ Radiation
☐ Chemoradiation (concurrent chemotherapy and radiation)
☐ Targeted therapy
☐ Stem cell transplant
    ☐ Autologous SCT
    ☐ Allogeneic SCT
☐ Bisphosphonate/s
☐ Other: ___________

Appendix E. Survey for the Qualitative Study

Survey

Please respond to each question or statement by marking one box per row.

In the past 7 days…

	Never	Rarely	Sometimes	Often	Always
1. I felt worthless	☐	☐	☐	☐	☐
2. I felt helpless	☐	☐	☐	☐	☐
3. I felt depressed	☐	☐	☐	☐	☐
4. I felt hopeless	☐	☐	☐	☐	☐
5. I felt fearful	☐	☐	☐	☐	☐
6. I found it hard to focus on anything other than my anxiety	☐	☐	☐	☐	☐
7. My worries overwhelmed me	☐	☐	☐	☐	☐
8. I felt uneasy	☐	☐	☐	☐	☐

The following statements describe how people sometimes feel. For each statement, please indicate how often you feel the way described by writing a number in the space provided. Here is an example:

How often do you feel happy?

If you never felt happy, you would respond “never”; if you always feel happy, you would respond “always.”

NEVER	RARELY	SOMETIMES	ALWAYS
1	2	3	4

1. How often do you feel that you are “in tune” with the people around you? _______

2. How often do you feel that you lack companionship? _______

3. How often do you feel that there is no one you can turn to? _______

4. How often do you feel alone? _______

5. How often do you feel part of a group of friends? _______

6. How often do you feel that you have a lot in common with the people around you? _______

7. How often do you feel that you are no longer close to anyone? _______

8. How often do you feel that your interests and ideas are not shared by those around you? _______

9. How often do you feel outgoing and friendly? _______

10. How often do you feel close to people? _______

11. How often do you feel left out? _______

12. How often do you feel that your relationships with others are not meaningful? _______

13. How often do you feel that no one really knows you well? _______

14. How often do you feel isolated from others? _______

15. How often do you feel you can find companionship when you want it? _______

16. How often do you feel that there are people who really understand you? _______

17. How often do you feel shy? _______

18. How often do you feel that people are around you but not with you? _______

19. How often do you feel that there are people you can talk to? _______

20. How often do you feel that there are people you can turn to? _______

General Information

1. How many relatives do you see or talk to at least once every 2 weeks? ____

2. How many friends do you see or talk to at least once every 2 weeks? ____

3. If you are currently employed, how many co-workers do you see or talk to at least once every 2 weeks? ____

(If you are not currently employed, please skip to question #4.)

4. How many cancer patients or survivors do you see or talk to at least once every 2 weeks? ____

5. How many cancer patients or survivors do you know that you feel comfortable sharing your experiences with? ____

6. On a scale from 1-10, how would you rate the overall quality of your relationships?

1 2 3 4 5 6 7 8 9 10

(worst quality you can imagine) (best quality you can imagine)

7. What race or ethnicity do you consider yourself to be?

___White ___Black or African American ___Asian-American or Pacific Islander

___Native American ___Hispanic or Latino ___Multi-racial

___Other (please specify)___________________________

8. Marital Status (check one) ___Single ___Living with partner ___Married

___Separated ___Divorced ___Widowed

9. Employment status (check one) ___Employed full-time ___Employed part-time

___Student ___Homemaker ___Retired

___Unemployed, looking for work ___Unemployed, due to disability

___Other (please specify): _______________________________

10. What is the highest grade or year of school you completed?

___Never attended school or only attended kindergarten

___Grades 1 through 8 (Elementary)

___Grades 9 through 11 (Some high school)

___Grade 12 or GED (High school graduate)

___College 1 year to 3 years (Some college or technical school)

___ College 4 years or more (College graduate)

___ Graduate school (Master's degree, Doctorate, etc.)

11. Do you have health insurance coverage now?

____Yes _____ No

THANK YOU FOR YOUR PARTICIPATION!

Appendix F. Qualitative Interview Guide

Semi-structured Qualitative Interview Guide and Handouts

Now I am going to ask you some questions about your experiences since your cancer diagnosis.

1. Many cancer patients say they feel lonely at times. Since your cancer diagnosis, can you think of a time when you felt lonely?

2. How would you describe how that felt to someone else?

Thanks for sharing that with me. For this project, loneliness means feeling isolated or disconnected from others around you. It isn't about how *much* time you spend with others or how many friends you have, but more about how connected you feel with others overall. Does that make sense? *(answer questions as necessary*)

3. Have you had an experience when you felt isolated or disconnected from family or friends since your cancer diagnosis? Tell me about that. (*do not ask this question if previous description clearly refers to my definition of loneliness)*

4. What thoughts were going through your head as you had this experience? *(do not ask this question if they shared thoughts in previous responses)*

5. What happened that caused those thoughts [or emotions]? (*do not ask this question if they shared events in previous responses)*

Now I'd like to change our focus and talk about a questionnaire on loneliness that we are developing. The purpose of the questionnaire is to see if cancer patients are feeling lonely. The questionnaire is not perfect and we could really use your help in improving it. Here is a copy [*hand the patient the questionnaire*]. I would like you to read the questionnaire and let me know what you like about it and what you do not like. Some people are not comfortable giving negative feedback, but I encourage you to be critical, as this will help us improve the questionnaire.

I am interested in how clear the questions are, if they are easy or difficult to read, if they make sense to you, and if anything is missing. Please take your time to carefully read through them. If a question doesn't make sense, isn't clear enough, is missing something, or has any problems with it, please circle it. After you have finished, we will discuss it.

6. Overall, how clear are the questions?

7. Now, let's take a look at any individual questions you circled. What are your thoughts? (*if applicable*)

Probes (*if applicable*):

- What does that question mean to you?
- How would you phrase that [question or word] in your own words?
- How easy or difficult was it to answer that question?

If a person says they have not been lonely: Ok. A lot of patients say they do feel lonely at times. As we continue our conversation, let me know if you think of any times when you felt that way. (*skip to definition*). If a person still says they haven’t experienced it: Ask if they’d still be willing to help me by telling me if any questions are hard or easy to read or have any problems with them.

Prompt if person has a hard time describing their experience: If you were talking to someone, what would you need to tell them so they could understand what it’s like for you?

Appendix G. Sample Characteristics for the Qualitative Study

Table G1.

Sample Characteristics (N = 15)

Characteristic	*N* (%)	*M* (*SD*)	Range
Average age		62.6 (11.9)	43.0-77.0
Female gender	7 (46.7)		
Marital status			
Never married	2 (13.3)		
Married/living with partner	10 (66.6)		
Divorced or widowed	3 (20.0)		
Race/ethnicity			
White	14 (93.3)		
African American	1 (6.7)		
Education level			
Some high school	1 (6.7)		
High school graduate	4 (26.7)		
Some college or technical school	3 (20.0)		
College graduate	7 (46.7)		
Employment status			
Employed full or part-time	6 (40.0)		
Retired	6 (40.0)		
Unemployed due to disability	2 (13.3)		
Student	1 (6.7)		
Cancer type			
Multiple myeloma	8 (53.3)		
Non-Hodgkin’s lymphoma	7 (46.7)		
Cancer stage			
Early stage	5 (33.3)		
Late stage	10 (66.7)		
Years since diagnosis		2.9 (3.2)	0.2-9.4

Table G1 continued next page.

Table G1 continued.

Characteristic	*N* (%)	*M* (*SD*)	Range
Treatments received			
Chemotherapy	14 (93.3)		
Autologous stem cell transplant	7 (46.7)		
Targeted therapy	6 (40.0)		
Bisphosphonate	4 (26.7)		
Other surgery	1 (6.7)		
Radiation	1 (6.7)		
Loneliness		31.1 (8.3)	21.0-48.0
Depression		2.1 (2.1)	0.0-6.0
Anxiety		2.7 (2.3)	0.0-7.0
Social network characteristics			
Num. relatives		5.6 (4.6)	0.0-18.0
Num. friends		9.3 (12.6)	0.0-50.0
Num. coworkers		9.0 (5.9)	1.0-20.0
Num. cancer patients		1.2 (1.4)	0.0-5.0

Appendix H. Cancer-related Negative Social Expectations Scale Items by Domain

Domain 1: Expecting others to listen or be available whenever the patient needs them.

1. I expect people to always be available for me because of my cancer.

2. I expect people to listen to me whenever I want to talk about my cancer.

3. If people stopped asking about my cancer, I would think that they don’t care.

4. If people avoided discussing my cancer with me, I would think that they didn’t want to hear about it.

5. If people avoided seeing or talking to me after my cancer diagnosis, I would think that they don’t care.

Domain 2: Expecting a lack of understanding of cancer-related concerns.

6. People will not understand if I share my concerns about cancer.

7. People could not truly understand how I feel about my cancer diagnosis.

Domain 3: Expecting that others will not understand existential thoughts.

8. People would not understand my thoughts about death since my cancer diagnosis.

9. People would not understand my uncertainty about the future since my cancer diagnosis.

Domain 4: Expecting sharing cancer-related concerns to burden others.

10. If I shared my concerns about cancer with people then it would be too hard on them.

11. I would burden people if I shared my thoughts and feelings about cancer with them.

Domain 5: Expecting telling others about their diagnosis or cancer-related concerns to change their relationships for the worse.

12. If I told people about my cancer experience, they would be nervous and uncomfortable around me.

13. If I told people about my cancer experience, our relationship would change for the worse.

14. If I shared my concerns about cancer with people then they might hurt me with their reactions.

Appendix I. Introductory Mailings for Quantitative Study

<DATE>

Dear <TITLE, NAME>,

The physicians and staff at the Indiana University Cancer Center and other Indiana University Health hospitals are interested in improving services and meeting the needs of our patients. We would like to know more about the impact of cancer and its treatment on patients' lives.

We are writing to tell you about a new research study which may be of interest to you. Cancer patients who have received services at an Indiana University Health hospital are invited to participate in this research study. If you agree to participate, you will be asked to complete a mailed questionnaire that asks for information about your background, physical health status (pain, energy level, etc.), social relationships, and mood. We understand that the information you may provide is personal and it will be kept private. The enclosed consent and authorization forms provide more information about this study.

In the next few weeks, a member of our research team will contact you by phone to explain the study, answer your questions, and invite you to take part. Although you are free to choose not to participate in this study, your participation would help the healthcare team better understand the experiences of people with cancer. Additionally, after completing the questionnaire, we would mail you a $25 Target gift card to show our appreciation.

If you do not wish for us to call, or if you have any questions about the study, please call the research fellow, Rebecca Adams, at (317) 278-4009. Thank you very much for taking the time to consider this project.

Sincerely,

Catherine E. Mosher, Ph.D.
School of Science
Indiana University-Purdue University Indianapolis

Rafat Abonour, M.D.
Department of Medicine
Indiana University School of Medicine

INDIANA UNIVERSITY STUDY INFORMATION SHEET FOR

Health and Social Well-Being among Cancer Patients

You are invited to participate in a research study about the social experiences of cancer patients. You were selected as a possible subject because you have been diagnosed with cancer. We ask that you read this form and ask any questions you may have before agreeing to be in the study.

The study is being conducted by Dr. Catherine Mosher, Assistant Professor of Psychology at the IUPUI School of Science. It is funded by the National Cancer Institute.

STUDY PURPOSE

The purpose of this study is to learn about cancer patients' health and social experiences. We will use the information from this study to improve support services for patients in the future.

NUMBER OF PEOPLE TAKING PART IN THE STUDY:

If you agree to participate, you will be one of 260 subjects who will be participating in this research.

PROCEDURES FOR THE STUDY:

If you agree to be in the study, you will do the following things:

If you choose to take part in this study, we will mail you a paper survey to fill out at home. It will take about 10 to 20 minutes. The survey includes questions about you. These include:

- Your education and employment
- Your mood
- Your physical symptoms
- Your relationships
- Your experience coping with cancer

After you take the survey, you will mail it back to the study team. We will provide a postage-paid return envelope for you to use.

If you choose to take part in this study, we will collect the following information from your IU Health medical records:

- Age
- Gender
- The date you were diagnosed with cancer
- The type of cancer you were diagnosed with
- The stage of the cancer
- Your treatments for cancer (surgery, radiation, chemotherapy, or other treatments)

RISKS OF TAKING PART IN THE STUDY:

While on the study, there is a risk that you will feel uncomfortable with some of the questions. You may skip any of the questions. Another risk of taking part in the study is that you may experience some distress, including anxiety, sadness, or negative thoughts. If you do experience distress, then you may contact the study investigator and psychologist, Dr. Catherine Mosher (phone: 317-274-6769). You may also contact Dr. Mosher with any questions or concerns about the study.

There is also a risk of possible loss of confidentiality. We will protect your information to the limit of the law. We will keep your information in passphrase protected electronic files or in lockable file cabinets in a private office. When the study ends, we will remove all identifying information from study data and materials. There is also a risk of loss of confidentiality since members of our research team will know you and the information you share. Your information will be kept confidential and only members of the research team will have access to your records. Unless law requires us, we will not share that information with anyone.

BENEFITS OF TAKING PART IN THE STUDY:

You may not benefit directly from this study. Your taking part in this study may benefit other cancer patients in the future.

ALTERNATIVES TO TAKING PART IN THE STUDY:

You do not have to participate in this study if you do not want to.

CONFIDENTIALITY

Efforts will be made to keep your personal information confidential. We cannot guarantee absolute confidentiality. Your personal information may be disclosed if required by law. Your identity will be held in confidence in reports in which the study may be published.

Organizations that may inspect and/or copy your research records for quality assurance and data analysis include groups such as the study investigator and her research associates, the Indiana University Institutional Review Board or its designees, the study sponsor, and (as allowed by law) state or federal agencies, specifically the Office for Human Research Protections (OHRP), the National Cancer Institute (NCI), the National Institutes of Health (NIH), etc., who may need to access your medical and and/or research records.

PAYMENT

You will receive payment for taking part in this study. After you have completed the survey, you will be mailed a $25 Target gift card.

CONTACTS FOR QUESTIONS OR PROBLEMS

For questions about the study, contact the researcher Dr. Catherine Mosher at 317-274-6769. If you cannot reach the researcher during regular business hours (i.e. 8:00AM-5:00PM), please call the IU Human Subjects Office at (317) 278-3458 or (800) 696-2949.

For questions about your rights as a research participant or to discuss problems, complaints or concerns about a research study, or to obtain information, or offer input, contact the IU Human Subjects Office at (317) 278-3458 or (800) 696-2949 or by email at irb@iu.edu.

VOLUNTARY NATURE OF STUDY

Taking part in this study is voluntary. You may choose not to take part or may leave the study at any time. Leaving the study will not result in any penalty or loss of benefits to which you are entitled. Your decision whether or not to participate in this study will not affect your current or future relations with Indiana University Health hospitals.

INDIANA UNIVERSITY
AUTHORIZATION FOR THE RELEASE OF HEALTH INFORMATION FOR RESEARCH

Introduction: You have the right to decide who may review or use your Protected Health Information ("PHI"). The type of information that may be used is described below. When you consider taking part in a research study, you must give permission for your PHI to be released from your doctors, clinics, and hospitals to the research team, for the specific purpose of this research study.

<u>What does this authorization relate to?</u> This authorization relates to the following study:

Health and Social Well-Being among Cancer Patients	
TITLE OF THE RESEARCH	***IRB PROTOCOL #1406239341***
Catherine Mosher, Ph.D.	
PRINCIPAL INVESTIGATOR (in charge of Research Team)	***SPONSOR # R25 CA117865-06***
NAME OF RESEARCH PARTICIPANT	***BIRTHDATE***
STREET ADDRESS	***CITY, STATE & ZIP CODE***

<u>What information will be used for research purposes?</u> This form is to allow the release of your health information to be used for the research described above. Your health information includes information that can identify you. For example, it can include your name, address, phone number, birthday and medical record number.

This permission is for health care provided to you from the time of your cancer diagnosis until the end of this research study.

I understand the information listed below will be released and used for this research study:

- Age
- Gender
- The date you were diagnosed with cancer
- The type of cancer you were diagnosed with
- The stage of the cancer
- Your treatments for cancer (surgery, radiation, chemotherapy, or other treatments)

In the event of an adverse event, such as injury related to the research, other records may be accessed for the purposes of your treatment and/or for reporting purposes. This may include records from other health care providers from which you have received medical care, but who are not specifically listed in this Authorization.

<u>Specific authorizations:</u> I understand that this release also pertains to records concerning hospitalization or treatment that may include the categories listed below. I have the right to specifically request that records **NOT** be released from my health care providers to the Research Team. However, I understand that if I limit access to any of the records listed below, I ***will still*** be able to participate in this research study. Check limitations, if any, below:

☐ Mental health records
☐ Psychotherapy Notes
☐ HIV (AIDS)
☐ Other: ________________________

☐ Sexually transmitted diseases
☐ Alcohol / Substance abuse
☐ Sickle Cell Anemia

Who will be allowed to release this information?
I authorize the following persons, groups or organizations to disclose the information described in this Release of Information/Authorization for the above referenced research study:

- Indiana University Health: University Hospital

Who can access your PHI for the study? The people and entities listed above may share my PHI (or the PHI of the individual(s) whom I have the authority to represent), with the following persons or groups for the research study:

- The researchers and research staff conducting the study at Indiana University and IU Health
- Principal Investigator: ***Catherine Mosher, Ph.D.***
- The members and staff of the Human Subjects Office
- The members of the Institutional Review Boards (IRB) that approve this study
- Indiana University and/or Indiana University affiliated institutions with compliance and financial oversight, including but not limited to:
    - Office of Research Compliance
    - Office of Research Administration
    - HIPAA Privacy and Security Compliance Office
    - General Counsel’s Office
    - Internal Audit
- US or foreign governments or agencies as required by law
- Federal agencies with research oversight responsibilities including but not limited to:
    - The United States Department of Health & Human Services (DHHS)
        - Office for Human Research Protections (OHRP)
        - Office for Civil Rights (OCR)
        - National Institutes of Health (NIH)
- Data and Safety Monitoring Boards and others authorized to monitor the conduct of the study

Expiration date of the authorization: This authorization is valid until the following date or event

☐ Date: __/__/____
☒ When the research ends and required monitoring of the study has been completed.
☐ Other: __________________ *[insert description of event or other circumstance. Examples: one year after death; one year after you reach age 50]*.
☐ None, this authorization is valid indefinitely

Efforts will be made to ensure that your PHI will not be shared with other people outside of the research study. However, your PHI may be disclosed to others as required by law and/or to individuals or organizations that oversee the conduct of research studies, and these individuals or organizations may not be held to the same legal privacy standards as are doctors and hospitals. Thus, the Research Team cannot guarantee absolute confidentiality and privacy.

I have the right:

1. To refuse to sign this form. Not signing the form will not affect my regular health care including treatment, payment, or enrollment in a health plan or eligibility for health care benefits. However, not signing the form will prevent me from participating in the research study above.

2. To review and obtain a copy of my personal health information collected during the study. However, it may be important to the success and integrity of the study that persons who participate in the study not be given access until the study is complete. The Principal Investigator has discretion to refuse to grant access to this information if it will affect the integrity of the study data during the course of the study. Therefore, my request for information may be delayed until the study is complete.

3. To cancel this release of information/authorization at any time. If I choose to cancel this release of information/authorization, I must notify the Principal Investigator for this study **in writing** at: Purdue School of Science, 402 North Blackford Street, LD 124, Indianapolis, IN 46202. However, even if I cancel this release of information/authorization, the Research Team, Research Sponsor(s) and/or the Research Organizations may still use information about me that was collected as part of the research project between the date I signed the current form and the date I cancel the authorization. This is to protect the quality of the research results. I understand that canceling this authorization may end my participation in this study.

4. To receive a copy of this form.

I have had the opportunity to review and ask questions regarding this release of information/authorization form. By signing this release of information/authorization, I am confirming that it reflects my wishes.

____
Printed name of Individual/Legal Representative

____
Signature of Individual/Legal Representative *Date*

**If signed by a legal representative; state the relationship and identify below the authority to act on behalf of the individual's behalf.*

***Individual is:** ☐ a Minor ☐ Incompetent ☐ Disabled ☐ Deceased

***Legal Authority:**

☐ Custodial Parent
☐ Executor of Estate of the Deceased
☐ Authorized Legal Representative
☐ Legal Guardian
☐ Power of Attorney Healthcare
☐ Other: ______________________

Appendix J. Telephone Scripts for Quantitative Study

Health and Social Well-Being among Cancer Patients

Note: This script is intended as a guideline only. However, research assistants must communicate all material included in the script.

DIRECTIONS FOR RESEARCH ASSISTANT:

"*Hello! May I speak with* **_______________________** (*Potential participant's name*)?"

- **If not available**: Do not leave your name or number to call back. Just say that you will call back another time and ask for a good time to reach them. (If they ask, you may tell them you are calling from Indiana University Health about a survey.)

- **If available**: *Hello Mr./Ms.* **_______**. *My name is* **_________**. *I work at Indiana University Health with Dr. Mosher and Dr. Abonour. How are you doing today?*

I am calling to follow up on a letter we mailed to you about a survey that we are working on here. Did you receive our letter and study information forms? Did you have a chance to read these materials?

If not/does not recall receiving a letter from us: *The letter we sent was asking for your help in an important survey being conducted at the Indiana University Health Cancer Center and University Hospital.*

Would now be a good time to speak with you regarding this study? Our conversation will take about 10 to 15 minutes.

If no: *When would be a better time for me to call?*

If refused: say, *Okay. For my records, may I ask the reason you prefer not to participate?* [Pause and note reason—if it's based on an inaccurate impression, correct it and ask if that would change their mind about participating. Try gently to have the person elaborate as much as possible on the reason. Document the patient's gender, age, and race if s/he is willing to provide this information.] *Would you be willing to provide your gender, age, and race for our records? Thank you. I appreciate your time. If you change your mind, feel free to call the number for this study—it's on the letter you were sent.*

If yes: Continue to next section.

(*As you may have read in the materials we sent you. . .) We are asking you to be in this study because you have recently received treatment for cancer at an IU Health hospital.*

We are doing this study to learn about cancer patients' health and social experiences. We will use the information from this study to improve support services for patients in the future. I should tell you that the entire study is done by mail. If you are interested in participating in this study, we will mail you a paper survey to fill out at home and a postage-paid envelope for returning it to us. It will take about 10 to 20 minutes. The survey includes questions about your background, your mood, your physical symptoms, your relationships, and your experience coping with cancer. There will be no financial costs to you for participating in this study. Participants will receive a $25 Target gift card for participating. Do you have any questions?

I'm going to summarize the study information sheet and authorization form for your information, okay? [If patient does not have a copy of the study information sheet, say *I will mail a copy of the study information sheet for your records* (Verify address for mailing the Study Information Sheet. You must read the entire form if they did not receive it)].

Your participation in this study is completely voluntary. You may choose either to take part or not to take part in the study. If you decide to take part in this study, you may leave the study at any time. No matter what decision you make, there will be no penalty to you and you will not lose any of your regular benefits. Leaving the study will not affect your medical care.

Also, with your permission, we would like to collect some limited health information from your medical records, including your age, gender, the date you were diagnosed with cancer, the type of cancer you were diagnosed with, the stage of the cancer, and your treatment for cancer. The reason we would like to collect this information is to see how people's experiences might be different based upon things like the type of treatment they receive.

Every effort will be made to keep your information private. It is the responsibility of the research staff to protect your privacy. If information from this study is used in any reports or publications, your name and anything else that could identify you will not be used. Trained staff at Indiana University may review your study records if necessary. Access to your study records will be limited to those listed in the Authorization Form.

It's possible that you may experience feelings when you are completing the survey. These may be like the feelings you experience when talking to anyone in your life about your experiences with cancer. If that happens, you can always call us if you want to talk about it and we can refer you to services if needed.
Your participation in this study will contribute to a better understanding of the health and social well-being of cancer patients, which will lead to better services for cancer patients in the future. You may not benefit directly from this study.

You can talk to your study doctor about any questions or concerns you have about this study. Contact your study doctor, Dr. Catherine Mosher, at the number listed on the study information sheet. If you cannot reach Dr. Mosher during regular business hours, *please call the IU Human Subjects office at the numbers listed on the study information sheet.*

Do you have any questions? Do you agree to participate in this study?

(Participants should state YES or NO)

AUTHORIZATION CONSENT

There is just one last form I will summarize for your information, okay? It's called an Authorization form.

[If patient does not have a copy of the authorization form, say *I will mail a copy of the Authorization form for your records* (Verify address for mailing the Authorization form. You must read the entire authorization form if they did not receive it)].

I already told you about the limited information we collect from your medical records. This form tells you who may look at your information. That would just be the research team and medical staff who already have access to your records. There are also boards at Indiana University who may review this study to make sure your privacy is protected.

Do you have any questions for me about this form? Do you agree to give us permission to look at your health information?

(Participants should state YES or NO)

Thank you for agreeing to participate! You should keep both of these forms for your records. You should not send them back to us.

Next, we will send you an envelope in the mail with a paper survey for you to fill out at home. We will also include a postage-paid envelope for returning the survey to us. To protect your privacy, please do not put your name, address, or other information that could identify you on the survey or envelope. We will use a study identification number on the top of the survey to identify you. Once we have received your survey, we will mail your $25 Target gift card to you! Do you have any questions for me now? If you have any questions in the future, please feel free to call us at the number provided in the letter [(317) 278-4009].

We greatly appreciate your interest! It was great to talk to you today. Thank you again!

SCRIPT FOR LEAVING A MESSAGE

Hello, this message is for_________. My name is __________ and I am calling from IU Health to follow-up on a letter we sent you about a research study. Please call us back to let us know if you are interested in participating or have questions. Our phone number is 317-278-4009. Thank you so much!

Appendix K. Informed Consent Process Documentation Form for Quantitative Study

IRB Protocol 1406239341: Health and Social Well-being among Cancer Patients

Informed Consent Process Documentation for Research Assistants

Study ID #:___________

I spoke with the person regarding the above-referenced study on __________.
(date)

- ☐ The person was given information regarding study procedures, benefits, risks, alternatives to study participation, voluntary nature of research participation, confidentiality issues and ability to withdraw from study participation, as well as information specific to the HIPAA authorization form.
- ☐ The person was provided adequate time and opportunity to review the Study Information Sheet and authorization form and all questions regarding information in these forms were adequately answered.
- ☐ The person verbalized understanding of the contents of the Study Information Sheet before providing verbal consent for study participation.
- ☐ No study-specific procedures were done prior to obtaining verbal consent for study participation.
- ☐ The person was mailed a copy of the Study Information Sheet and the HIPAA Authorization form.
- ☐ The Study Information Sheet and authorization form were the latest IRB approved versions.

Additional Comments:

____

____

____

____

Consenter's Signature:_________________________

Date:____________________

Appendix L. Survey Mailings for Quantitative Study

<DATE>

Dear <TITLE, NAME>,

The physicians and staff at the Indiana University Cancer Center and other Indiana University Health hospitals thank you again for agreeing to participate in our study. We really value your experiences!

Some reminders about the survey:

- To protect your privacy, remember not to put your name, address, or other information that could identify you on the survey or envelope. We will use a study identification number on the top of the survey to identify you.
- When you have completed the survey, please return it to us using the postage-paid envelope that is provided.
- Once we have received your survey, we will mail your $25 Target gift card to you!

If you have any questions about the study, please call the research fellow, Rebecca Adams, at
(317) 278-4009.

Thanks again for your participation!

Sincerely,

Catherine E. Mosher, Ph.D.
School of Science
Indiana University-Purdue University Indianapolis

Rafat Abonour, M.D.
Department of Medicine
Indiana University School of Medicine

Study ID # _______

IU Health Survey

Please respond to each item by marking one box per row.

	Excellent	Very Good	Good	Fair	Poor
1. In general, would you say your health is:	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
2. In general, would you say your quality of life is:	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
3. In general, how would you rate your physical health?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
4. In general, how would you rate your mental health, including your mood and your ability to think?..	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
5. In general, how would you rate your satisfaction with your social activities and relationships?	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
6. In general, please rate how well you carry out your usual social activities and roles. (This includes activities at home, at work and in your community, and responsibilities as a parent, child, spouse, employee, friend, etc.)............	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
7. To what extent are you able to carry out your everyday physical activities such as walking, climbing stairs, carrying groceries, or moving a chair?...	☐ 5	☐ 4	☐ 3	☐ 2	☐ 1
In the past 7 days…					
	Never	Rarely	Sometimes	Often	Always
8. How often have you been bothered by emotional problems such as feeling anxious, depressed or irritable?	☐	☐	☐	☐	☐
	None	Mild	Moderate	Severe	Very severe
9. How would you rate your fatigue on average?	☐	☐	☐	☐	☐

---

10. How would you rate your pain on average?	☐ 0 No pain	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5	☐ 6	☐ 7	☐ 8	☐ 9	☐ 10
										Worst imaginable pain	

Please respond to each question or statement by marking one box per row.

In the past 7 days…

	Not at all	A little bit	Somewhat	Quite a bit	Very much
1. How much did pain interfere with your day to day activities?	☐	☐	☐	☐	☐
2. How much did pain interfere with work around the home?	☐	☐	☐	☐	☐
3. How much did pain interfere with your ability to participate in social activities?....	☐	☐	☐	☐	☐
4. How much did pain interfere with your household chores?	☐	☐	☐	☐	☐
5. My sleep was refreshing.	☐	☐	☐	☐	☐
6. I had a problem with my sleep	☐	☐	☐	☐	☐
7. I had difficulty falling asleep	☐	☐	☐	☐	☐
8. How run-down did you feel on average? …………………………..	☐	☐	☐	☐	☐
9. How fatigued were you on average?	☐	☐	☐	☐	☐

During the past 7 days…

	Not at all	A little bit	Somewhat	Quite a bit	Very much
10. I feel fatigued	☐	☐	☐	☐	☐
11. I have trouble <u>starting</u> things because I am tired	☐	☐	☐	☐	☐

	Very poor	Poor	Fair	Good	Very good
12. My sleep quality was	☐	☐	☐	☐	☐

In the past 7 days…	Never	Rarely	Sometimes	Often	Always
13. I felt worthless	☐	☐	☐	☐	☐
14. I felt helpless	☐	☐	☐	☐	☐
15. I felt depressed	☐	☐	☐	☐	☐
16. I felt hopeless	☐	☐	☐	☐	☐
17. I felt fearful	☐	☐	☐	☐	☐
18. I found it hard to focus on anything other than my anxiety	☐	☐	☐	☐	☐
19. My worries overwhelmed me	☐	☐	☐	☐	☐
20. I felt uneasy	☐	☐	☐	☐	☐

In the past 7 days…	Never	Rarely (once)	Sometimes (2-3 times)	Often (once a day)	Very often (several times a day)
21. My thinking has been slow	☐	☐	☐	☐	☐
22. It has seemed like my brain was not working as well as usual………………	☐	☐	☐	☐	☐
23. I have had to work harder than usual to keep track of what I was doing	☐	☐	☐	☐	☐
24. I have had trouble shifting back and forth between different activities that require thinking………..............................	☐	☐	☐	☐	☐

The following statements describe how people sometimes feel. For each statement, please indicate how often you feel the way described by writing a number in the space provided. Here is an example:
How often do you feel happy?
If you never felt happy, you would respond "never"; if you always feel happy, you would respond "always."

NEVER	RARELY	SOMETIMES	ALWAYS
1	2	3	4

1. How often do you feel that you are "in tune" with the people around you? _______

2. How often do you feel that you lack companionship? _______

3. How often do you feel that there is no one you can turn to? _______

4. How often do you feel alone? _______

5. How often do you feel part of a group of friends? _______

6. How often do you feel that you have a lot in common with the people around you? _______

7. How often do you feel that you are no longer close to anyone? _______

8. How often do you feel that your interests and ideas are not shared by those around you? _______

9. How often do you feel outgoing and friendly? _______

10. How often do you feel close to people? _______

11. How often do you feel left out? _______

12. How often do you feel that your relationships with others are not meaningful? _______

13. How often do you feel that no one really knows you well? _______

14. How often do you feel isolated from others? _______

15. How often do you feel you can find companionship when you want it? _______

16. How often do you feel that there are people who really understand you? _______

17. How often do you feel shy? _______

18. How often do you feel that people are around you but not with you? _______

19. How often do you feel that there are people you can talk to? _______

20. How often do you feel that there are people you can turn to? _______

The following statements describe how people sometimes feel after being diagnosed with cancer. For each statement, please indicate how often you have felt that way by writing a number in the space provided. Please note that the response options are now 1 to 5.

NEVER	RARELY	SOMETIMES	OFTEN	ALWAYS
1	2	3	4	5

1. Since your cancer diagnosis, how often have you felt that people are around you but not with you? ______

2. How often do you feel left out because of your cancer? ______

3. Since your cancer diagnosis, how often have you felt that you were not important to others? ______

4. How often do you feel that there is no one you can share the ups and downs of cancer with? ______

5. How often does having cancer make you feel empty? ______

6. Since your cancer diagnosis, how often have you felt misunderstood even by your closest friends and family members? ______

7. How often do you feel that others cannot provide the support you need to deal with your cancer? ______

8. Since your cancer diagnosis, how often have you felt that you don't have a lot in common with the people around you? ______

9. How often do you feel that you cannot share personal thoughts about cancer with anyone? ______

10. Since your cancer diagnosis, how often have you felt that you were not needed by others? ______

11. How often does having cancer make you feel alone? ______

12. How often do you feel that no one really understands how cancer has affected you? ______

13. Since your cancer diagnosis, how often have you experienced a general sense of emptiness? ______

14. How often does your cancer diagnosis make you feel isolated from others? ______

15. Since your cancer diagnosis, how often have you felt that you are no longer close to anyone? ______

Please respond to each item by marking one box per row.

	Never	Rarely	Sometimes	Usually	Always
1. I have someone who will listen to me when I need to talk	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
2. I have someone to confide in or talk to about myself or my problems	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
3. I have someone who makes me feel appreciated	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
4. I have someone to talk with when I have a bad day	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
5. Do you have someone to help you if you are confined to bed?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
6. Do you have someone to take you to the doctor if you need it?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
7. Do you have someone to help with your daily chores if you are sick?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
8. Do you have someone to run errands if you need it?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Sometimes, even when people have good intentions, they may say or do things that upset you. Think about the PAST WEEK and indicate how often other people did the following things.

In the past 7 days…	Almost never				Almost always
1. How often did you feel as though you had to keep your feelings about your cancer to yourself because they made other people uncomfortable?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
2. How often did you feel that you could discuss your feelings about your cancer with other people when you wanted to?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
3. When you talked about your cancer, how often did other people give you the idea they didn’t want to hear about it?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
4. How often did you feel that other people let you down by not showing you as much love and concern as you would have liked?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5
5. How often have other people really got on your nerves?	☐ 1	☐ 2	☐ 3	☐ 4	☐ 5

Please respond to each item by marking one box per row.

	Strongly disagree	Moderately disagree	Slightly disagree	Slightly agree	Moderately agree	Strongly agree
1. If people stopped asking about my cancer, I would think that they don’t care…	☐	☐	☐	☐	☐	☐
2. People will not understand if I share my concerns about cancer…………………….	☐	☐	☐	☐	☐	☐
3. If I shared my concerns about cancer with people then it would be too hard on them..	☐	☐	☐	☐	☐	☐
4. People would not understand my thoughts about death since my cancer diagnosis ………………	☐	☐	☐	☐	☐	☐
5. I expect people to always be available for me because of my cancer ………………	☐	☐	☐	☐	☐	☐
6. If I told people about my cancer experience, they would be nervous and uncomfortable around me….	☐	☐	☐	☐	☐	☐
7. If people avoided discussing my cancer with me, I would think that they didn’t want to hear about it …	☐	☐	☐	☐	☐	☐
8. People could not truly understand how I feel about my cancer diagnosis ……	☐	☐	☐	☐	☐	☐
9. I would burden people if I shared my thoughts and feelings about cancer with them……………………..	☐	☐	☐	☐	☐	☐
10. People would not understand my uncertainty about the future since my cancer diagnosis………….	☐	☐	☐	☐	☐	☐

	Strongly disagree	Moderately disagree	Slightly disagree	Slightly agree	Moderately agree	Strongly agree
11. I expect people to listen to me whenever I want to talk about my cancer ………….….	☐	☐	☐	☐	☐	☐
12. If I told people about my cancer experience, our relationship would change for the worse ………………	☐	☐	☐	☐	☐	☐
13. If people avoided seeing or talking to me after my cancer diagnosis, I would think that they don't care …..	☐	☐	☐	☐	☐	☐
14. If I shared my concerns about cancer with people then they might hurt me with their reactions…………………..	☐	☐	☐	☐	☐	☐

General Information

1. How many relatives do you see or talk to at least once every 2 weeks? ____

   (*If you are not sure, please give your best guess.)*

2. How many friends do you see or talk to at least once every 2 weeks? ____

   (*If you are not sure, please give your best guess.)*

3. If you are currently employed, how many co-workers do you see or talk to at least once every 2 weeks? ____

   (If you are not currently employed, please skip to question #4.)

4. How many cancer patients or survivors do you see or talk to at least once every 2 weeks? ____

5. How many cancer patients or survivors do you know that you feel comfortable sharing your experiences with? ____

6. On a scale from 1-10, how would you rate the overall quality of your relationships?

1	2	3	4	5	6	7	8	9	10

(worst quality you can imagine) (best quality you can imagine)

7. Have you attended a support group for cancer patients? ____ Yes _____No

8. What race or ethnicity do you consider yourself to be?

___White ___Black or African American ___Asian-American or Pacific Islander

___Native American ___Hispanic or Latino ___Multi-racial

___Other (please specify)__________________________

9. Marital Status (check one)

___Single ___Living with partner ___Married ___Separated ___Divorced

___Widowed

10. Employment status (check one)

___Employed full-time ___Employed part-time ___Student ___Homemaker

___Retired ___Unemployed, looking for work ___Unemployed due to disability

___Other (please specify) ______________________________

11. What is the highest grade or year of school you completed?

___Never attended school or only attended kindergarten

___Grades 1 through 8 (Elementary)

___Grades 9 through 11 (Some high school)

___Grade 12 or GED (High school graduate)

___College 1 year to 3 years (Some college or technical school)

___ College 4 years or more (College graduate)

___ Graduate school (Master's degree, Doctorate, etc.)

12. Do you have health insurance coverage now?

____Yes ______ No

THANK YOU FOR YOUR PARTICIPATION!

Appendix M. Quantitative Study Flow Chart

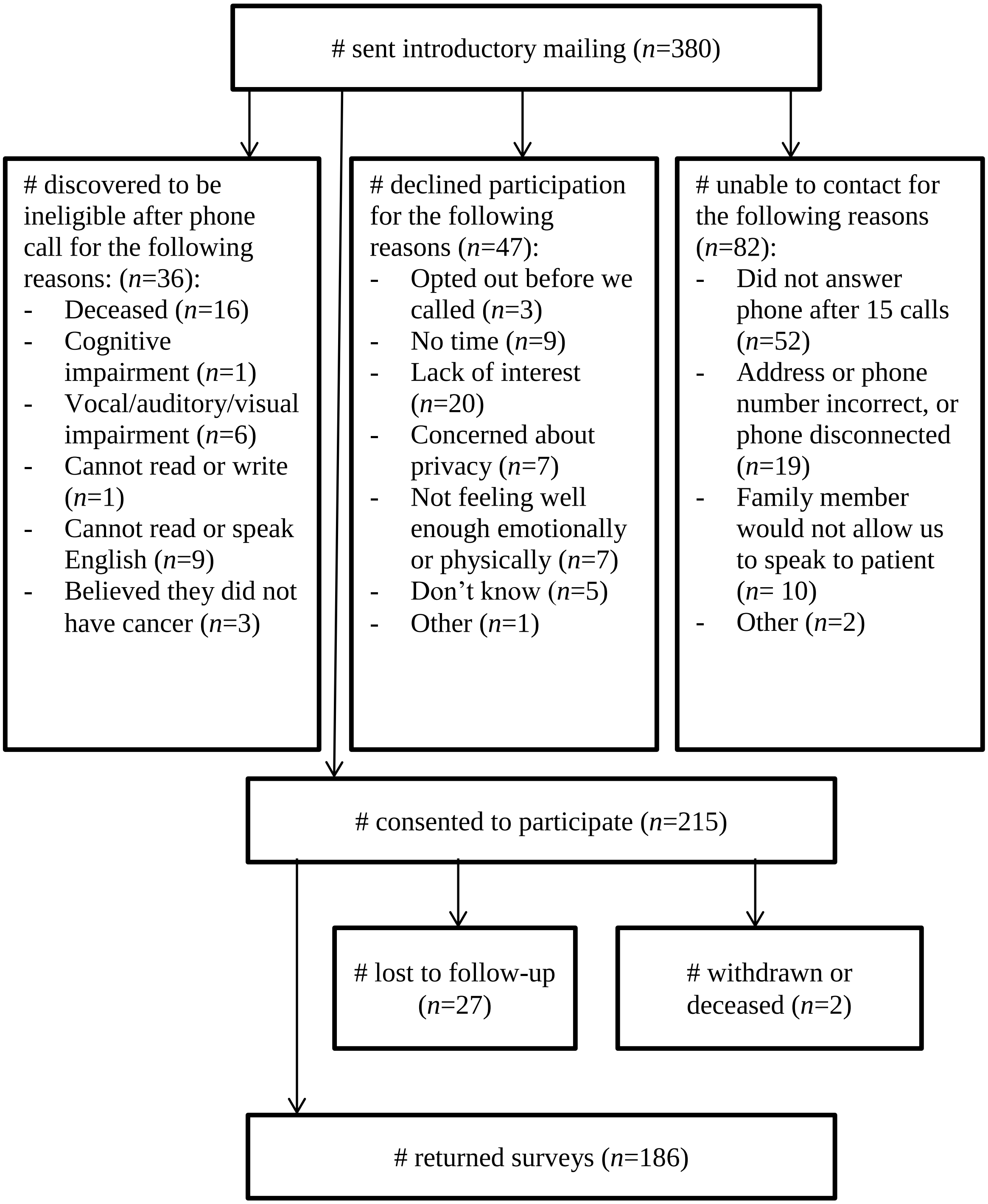

Figure M1.

Quantitative Study Flow Chart

Note. Multiple reasons could be selected for non-participation.

Appendix N. Sample Characteristics and Preliminary Analyses for Quantitative Study

Table N2.

Sample Characteristics (N = 186)

Characteristic	*N* (%)	*M* (*SD*)	Range
Average age		59.3 (12.6)	21.0-87.0
Female gender	95 (51.1)		
Race/ethnicity			
White	138 (74.2)		
Black or African American	41 (22.0)		
Multi-racial	3 (1.6)		
Hispanic or Latino	2 (1.1)		
Asian-American or Pacific Islander	2 (1.1)		
Marital status			
Married/living with partner	126 (67.7)		
Divorced, separated, or widowed	39 (21.0)		
Never married	21 (11.3)		
Education level			
Elementary or some high school	14 (7.5)		
High school graduate	63 (33.9)		
Some college or technical school	56 (30.1)		
College graduate	53 (28.5)		
Employment status			
Employed full or part-time	77 (41.4)		
Retired	64 (34.4)		
Unemployed due to disability	31 (16.7)		
Homemaker	6 (3.2)		
Unemployed, looking for work	3 (1.6)		
Student	2 (1.1)		
Other	2 (1.1)		
Missing	1 (0.5)		

Table N2 continued next page.

Table N2 continued.

Characteristic	*N* (%)	*M* (*SD*)	Range
Cancer stage			
Early stage	117 (62.9)		
Late stage	46 (24.7)		
N/A staging system	9 (4.8)		
Missing	14 (7.5)		
Months since diagnosis		16.7 (3.2)	1.0-24.3
Treatments received			
Surgery	154 (82.8)		
Chemotherapy	71 (38.2)		
Radiation	61 (32.8)		
Hormone therapy	36 (19.4)		
Immunotherapy	15 (8.1)		
Stem cell transplant	4 (2.2)		
Other	2 (1.1)		

Table N3.

Descriptive Statistics for Health and Social Well-being Variables (N=186)

Variable	n	Mean	Standard deviation	Range	Skew	Kurtosis	t-score[a]
Cancer-related loneliness	185	13.7	6.6	7.0-35.0	0.99	0.30	
Negative social expectations	185	13.9	6.9	5.0-30.0	0.32	-0.91	
Emotional social support	184	17.0	3.7	4.0-20.0	-1.3	1.0	
Depression	185	7.1	3.5	4.0-18.0	1.0	0.0	51.0
Anxiety	185	7.3	3.4	4.0-19.0	1.0	0.3	51.5
Pain	185	7.8	4.5	4.0-20.0	0.9	-0.4	51.7
Fatigue	185	9.8	4.0	4.0-20.0	0.5	-0.5	52.4
Sleep disturbance	185	9.9	3.9	4.0-20.0	0.5	-0.4	
Mental quality of life	186	14.2	3.1	6.0-20.0	-0.4	-0.3	
Physical quality of life (4-item)	186	12.3	2.3	6.0-17.0	-0.5	-0.4	
Physical quality of life (3-item)	186	10.1	2.7	3.0-15.0	-0.4	-0.5	
Social constraints	185	9.5	4.2	5.0-25.0	1.2	1.1	
Loneliness	184	37.0	11.3	20.0-78.0	0.5	-0.1	
Num. relatives	183	5.9	4.3	0.0-30.0	2.6	11.0	
Num. relatives (winsorized)	183	5.8	3.6	0.0-18.7	1.4	2.8	
Num. friends	182	7.9	11.1	0.0-100.0	4.5	29.0	

Table N3 continued next page.

Table N3 continued.

Variable	n	Mean	Standard deviation	Range	Skew	Kurtosis	t-score[a]
Num. friends (winsorized)	182	7.4	8.3	0.0-41.2	2.3	6.2	
Num. coworkers	77	12.4	13.0	0.0-60.0	1.9	3.5	
Num. coworkers (winsorized)	77	12.3	12.6	0.0-51.6	1.8	2.8	
Num. cancer patients	177	1.6	2.5	0.0-25.0	5.6	45.3	
Num. cancer patients (winsorized)	177	1.5	1.7	0.0-9.2	1.7	4.4	

Note.

[a] T-scores are provided when the representative cancer patient sample data were available for calibration. See www.nihpromis.com for more information.

Appendix O. Proposed Confirmatory Factor Analysis Models

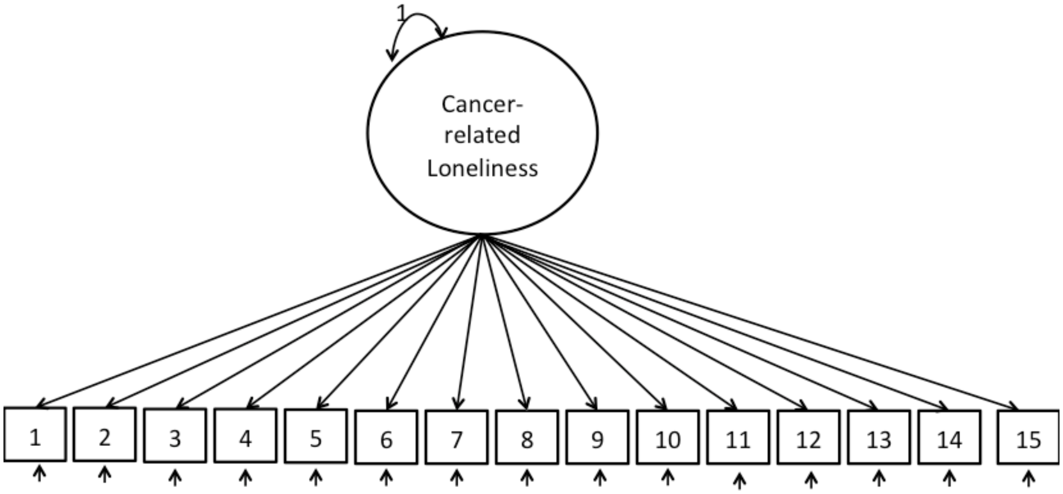

Figure O2.

Cancer Loneliness Scale (Unidimensional)

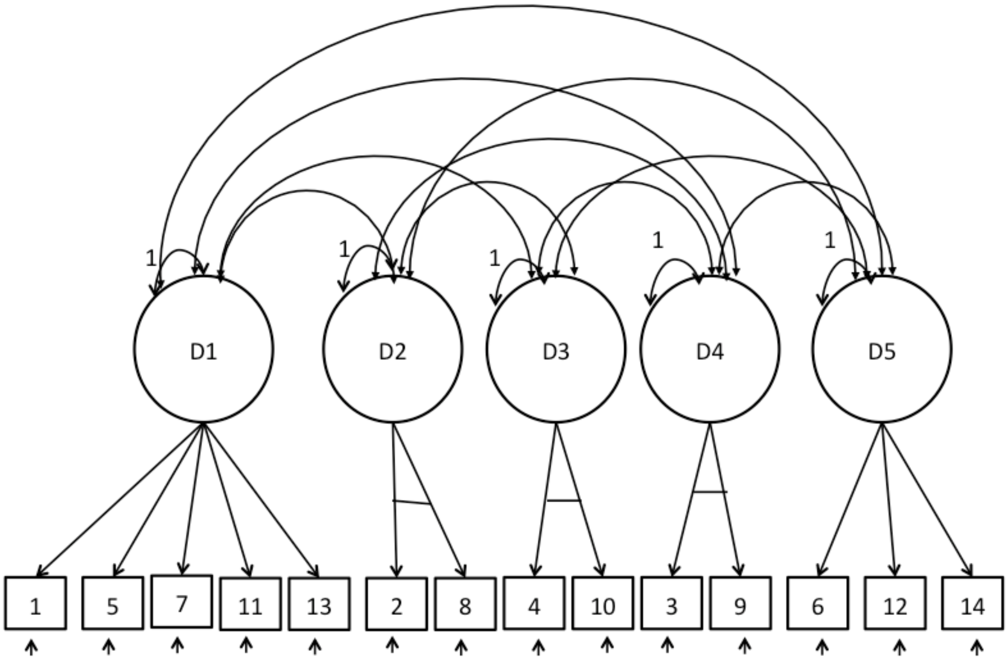

Figure O3.

Cancer-related Negative Social Expectations Scale (5-dimensional)

Note. Horizontal lines indicate that the pathways were constrained to be equal.

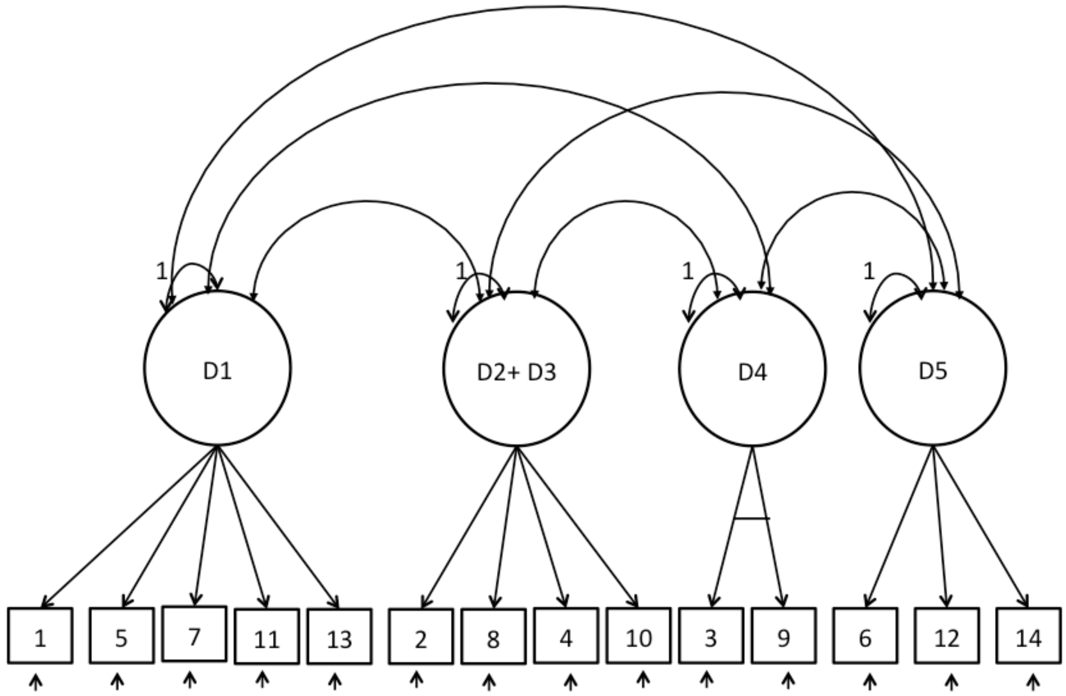

Figure O4.

Cancer-related Negative Social Expectations Scale (4-dimensional)

Note. The horizontal line indicates that the pathways were constrained to be equal.

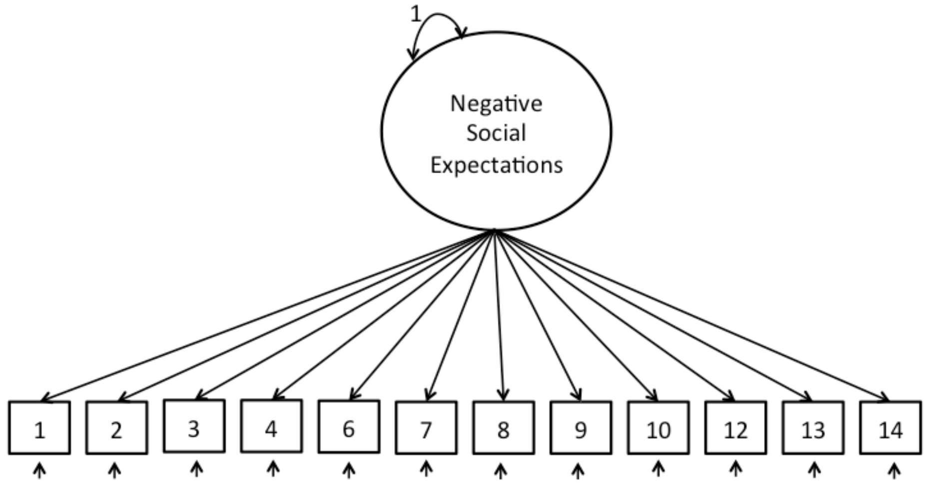

Figure O5.

Cancer-related Negative Social Expectations Scale (Unidimensional)

Appendix P. Quantitative Study Results

Table P4.

Descriptive Statistics for Cancer Loneliness Scale Items

Item	**M**	**SD**	**Item-total correlation**
1. Since your cancer diagnosis, how often have you felt that people are around you but not with you?	2.2	1.2	0.79
2. How often do you feel left out because of your cancer?	1.7	1.0	0.73
3. Since your cancer diagnosis, how often have you felt that you were not important to others?	1.7	1.0	0.82
4. How often do you feel that there is no one you can share the ups and downs of cancer with?	2.0	1.2	0.81
5. How often does having cancer make you feel empty?	2.1	1.2	0.78
6. Since your cancer diagnosis, how often have you felt misunderstood even by your closest friends and family members?	2.0	1.2	0.86
7. How often do you feel that others cannot provide the support you need to deal with your cancer?	1.9	1.2	0.79
8. Since your cancer diagnosis, how often have you felt that you don’t have a lot in common with the people around you?	1.9	1.0	0.73
9. How often do you feel that you cannot share personal thoughts about cancer with anyone?	2.1	1.2	0.82
10. Since your cancer diagnosis, how often have you felt that you were not needed by others?	1.8	1.1	0.82
11. How often does having cancer make you feel alone?	2.0	1.1	0.83
12. How often do you feel that no one really understands how cancer has affected you?	2.5	1.4	0.84
13. Since your cancer diagnosis, how often have you experienced a general sense of emptiness?	2.1	1.1	0.81
14. How often does your cancer diagnosis make you feel isolated from others?	2.0	1.1	0.86
15. Since your cancer diagnosis, how often have you felt you are no longer close to anyone?	1.7	1.0	0.81

Note. All *ns*= 185. All ranges = 1.0-5.0.

Table P5.

Inter-item Correlations for the Cancer Loneliness Scale Item Pool

	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15
1.	—														
2.	0.60	—													
3.	0.67	0.65	—												
4.	0.71	0.57	0.71	—											
5.	0.58	0.70	0.63	0.52	—										
6.	0.70	0.67	0.73	0.76	0.66	—									
7.	0.64	0.57	0.69	0.73	0.60	0.74	—								
8.	0.57	0.55	0.63	0.60	0.62	0.63	0.58	—							
9.	0.67	0.56	0.70	0.74	0.61	0.77	0.66	0.65	—						
10.	0.65	0.60	0.80	0.75	0.57	0.74	0.66	0.60	0.72	—					
11.	0.70	0.60	0.65	0.65	0.76	0.72	0.63	0.55	0.68	0.68	—				
12.	0.68	0.59	0.67	0.76	0.68	0.78	0.73	0.67	0.74	0.71	0.71	—			
13.	0.64	0.58	0.66	0.59	0.79	0.67	0.63	0.62	0.67	0.65	0.80	0.70	—		
14.	0.73	0.69	0.71	0.66	0.75	0.74	0.61	0.64	0.72	0.71	0.81	0.73	0.77	—	
15.	0.70	0.62	0.71	0.65	0.66	0.66	0.69	0.58	0.65	0.69	0.76	0.63	0.66	0.75	—

Note. All *ns*=185. All *ps*<0.01.

Table P6.

Item Selection for the Cancer Loneliness Scale

Items grouped by content	**Item-total correlations**	**Item retained**
1. Since your cancer diagnosis, how often have you felt that people are around you but not with you?	0.79	#14
2. How often do you feel left out because of your cancer?	0.73	
11. How often does having cancer make you feel alone?	0.83	
14. How often does your cancer diagnosis make you feel isolated from others?	0.86	
15. Since your cancer diagnosis, how often have you felt you are no longer close to anyone?	0.81	
3. Since your cancer diagnosis, how often have you felt that you were not important to others?	0.82	#10[a]
10. Since your cancer diagnosis, how often have you felt that you were not needed by others?	0.82	
4. How often do you feel that there is no one you can share the ups and downs of cancer with?	0.81	#9
9. How often do you feel that you cannot share personal thoughts about cancer with anyone?	0.82	
5. How often does having cancer make you feel empty?	0.78	#13
13. Since your cancer diagnosis, how often have you experienced a general sense of emptiness?	0.81	
6. Since your cancer diagnosis, how often have you felt misunderstood even by your closest friends and family members?	0.86	#6
7. How often do you feel that others cannot provide the support you need to deal with your cancer?	0.79	#7
8. Since your cancer diagnosis, how often have you felt that you don’t have a lot in common with the people around you?	0.73	#8
12. How often do you feel that no one really understands how cancer has affected you?	0.84	None[b]

[a] Item #10 was selected after examining additional indicators of item performance (e.g., distribution of participant responses).

[b] Although item #12 performed well, I decided to exclude it because the content is too similar to items in the Cancer-related Negative Social Expectations item pool.

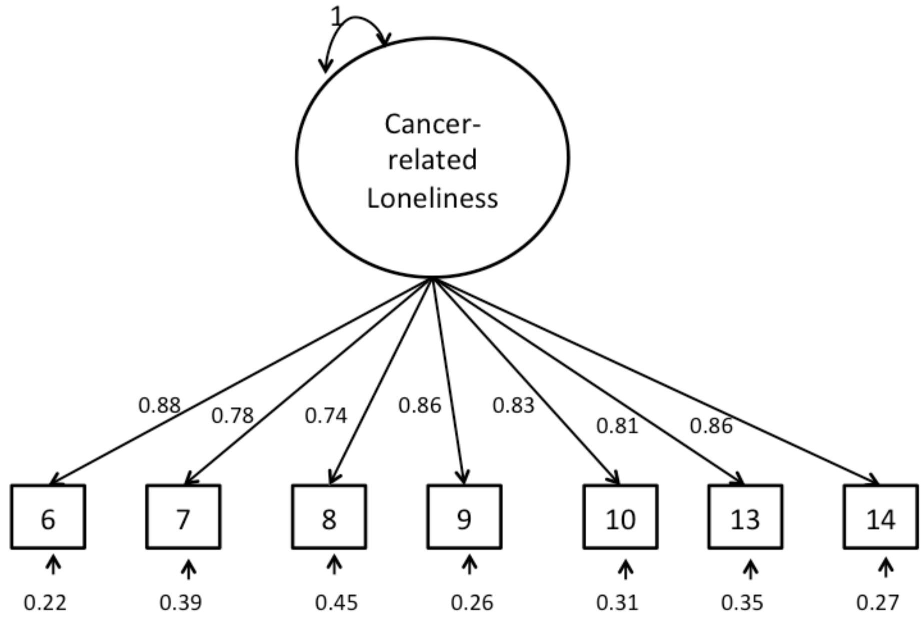

Figure P6.

Test of the Cancer-related Loneliness Model

Table P7.

Descriptive Statistics for the Cancer-related Negative Social Expectations Scale Items

Item	***n***	**M**	**SD**	**Item-total correlation**
1. If people stopped asking about my cancer, I would think that they don't care.	185	2.0	1.4	0.56
2. People will not understand if I share my concerns about cancer.	185	2.4	1.5	0.71
3. If I shared my concerns about cancer with people then it would be too hard on them.	185	2.5	1.5	0.69
4. People would not understand my thoughts about death since my cancer diagnosis.	185	2.9	1.7	0.75
5. I expect people to always be available for me because of my cancer.	185	2.0	1.4	0.16
6. If I told people about my cancer experience, they would be nervous and uncomfortable around me.	185	2.3	1.4	0.79
7. If people avoided discussing my cancer with me, I would think that they didn't want to hear about it.	185	2.7	1.6	0.67
8. People could not truly understand how I feel about my cancer diagnosis.	185	3.1	1.8	0.77
9. I would burden people if I shared my thoughts and feelings about cancer with them.	185	2.7	1.6	0.76
10. People would not understand my uncertainty about the future since my cancer diagnosis.	185	3.0	1.8	0.78
11. I expect people to listen to me whenever I want to talk about my cancer.	185	2.6	1.7	0.29
12. If I told people about my cancer experience, our relationship would change for the worse.	185	1.7	1.2	0.57
13. If people avoided seeing or talking to me after my cancer diagnosis, I would think that they don't care.	185	2.4	1.6	0.65
14. If I shared my concerns about cancer with people then they might hurt me with their reactions.	185	1.8	1.2	0.64

Table P5.

Inter-item Correlations for the Cancer-related Negative Social Expectations Scale

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.
1.	—													
2.	0.44**	—												
3.	0.45**	0.61**	—											
4.	0.43**	0.70**	0.70**	—										
5.	0.13	0.01	0.06	0.00	—									
6.	0.43**	0.63**	0.68**	0.67**	0.10	—								
7.	0.46**	0.43**	0.42**	0.49**	0.12	0.62**	—							
8.	0.44**	0.61**	0.57**	0.67**	0.16*	0.60**	0.56**	—						
9.	0.40**	0.61**	0.65**	0.70**	0.07	0.72**	0.61**	0.69**	—					
10.	0.42**	0.64**	0.61**	0.70**	0.14	0.66**	0.55**	0.72**	0.69**	—				
11.	0.33**	0.15*	0.04	0.08	0.33**	0.18*	0.26**	0.20**	0.10	0.21**	—			
12.	0.31**	0.50**	0.48**	0.48**	0.12	0.51**	0.40**	0.45**	0.50**	0.41**	0.14*	—		
13.	0.42**	0.46**	0.37**	0.46**	0.11	0.53**	0.58**	0.51**	0.45**	0.53**	0.45**	0.40**	—	
14.	0.37**	0.48**	0.45**	0.52**	0.06	0.58**	0.45**	0.54**	0.50**	0.54**	0.22**	0.46**	0.52**	—

Note. *Ns*=185-186.

* *p*<0.05

***p*<0.0

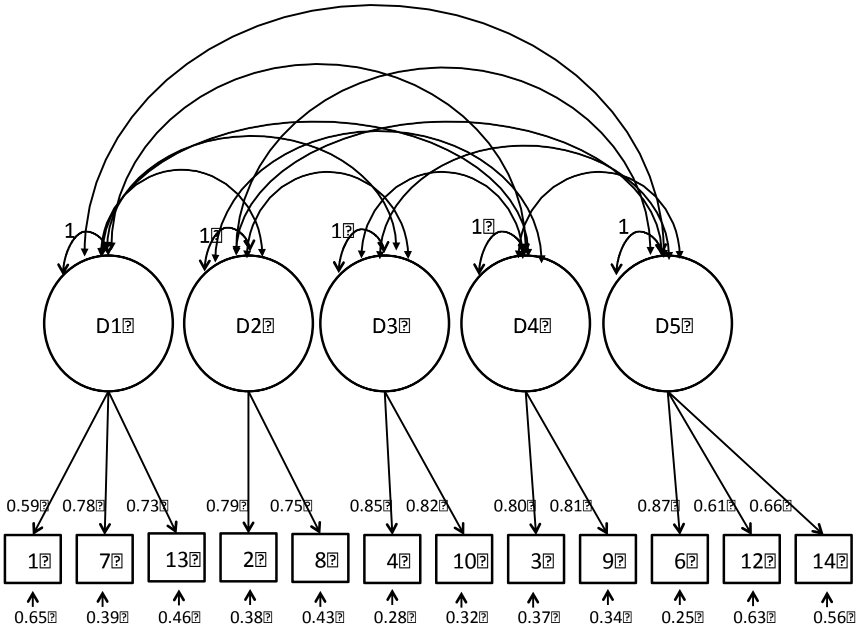

Figure P7.

Test of the 5-dimensional Cancer-related Negative Social Expectations Model

Table P9.

Standardized Psi Correlation Matrix for the 5-dimensional Cancer-related Negative Social Expectations Scale

Domain	1	2	3	4	5
1	—				
2	0.85	—			
3	0.80	1.05	—		
4	0.79	1.00	1.01	—	
5	0.88	0.94	0.91	0.98	—

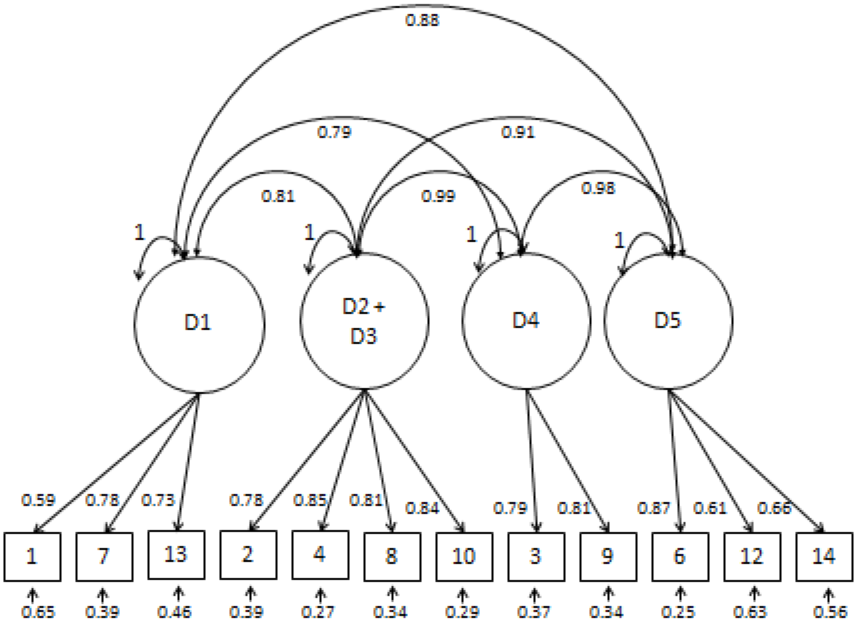

Figure P8.

Test of the 4-dimensional Cancer-related Negative Social Expectations Model

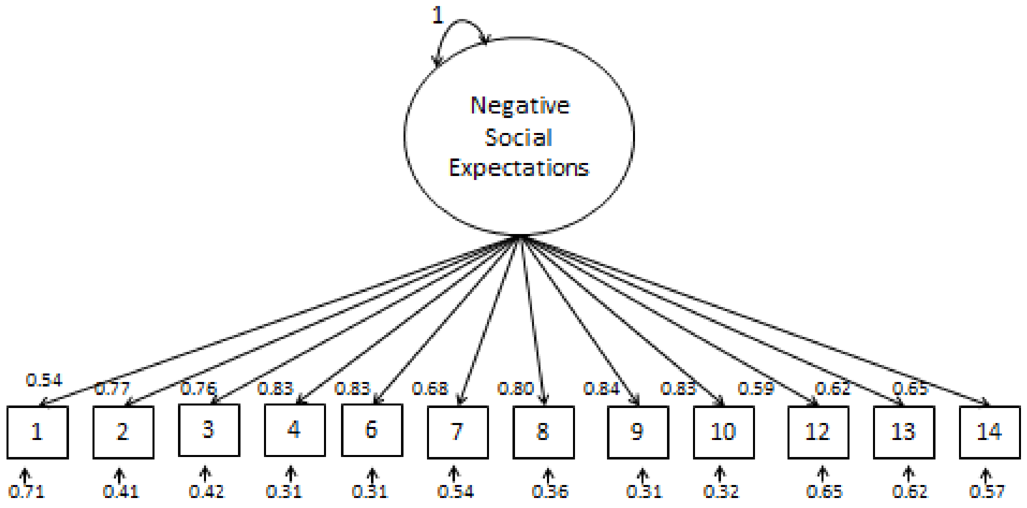

Figure P9.

Test of the Unidimensional Cancer-related Negative Social Expectations Model

Table P10.

Fit indices for the Cancer-related Negative Social Expectations Models

Model	Fit Indices		
	SRMR	RMSEA	CFI
5-dimensional model	0.06	0.07	0.99
4-dimensional model	0.04	0.07	0.99
Unidimensional model (12 items)	0.04	0.09	0.94
Unidimensional model (5 items)	0.02	0.11	0.98

Note. SRMR= standardized root mean square residual. RMSEA= root mean square error of approximation. CFI= comparative fit index.

Table P11.

Item Selection for the Cancer-related Negative Social Expectations Scale

Domain	**Items**	**Item-total correlations**	**Item retained**
1: Expecting others to listen or be available whenever the patient needs them.	1. If people stopped asking about my cancer, I would think that they don’t care.	0.56	#7
	5. I expect people to always be available for me because of my cancer.	0.16	
	7. If people avoided discussing my cancer with me, I would think that they didn’t want to hear about it.	0.67	
	11. I expect people to listen to me whenever I want to talk about my cancer.	0.29	
	13. If people avoided seeing or talking to me after my cancer diagnosis, I would think that they don’t care.	0.65	
2: Expecting a lack of understanding of cancer-related concerns	2. People will not understand if I share my concerns about cancer.	0.71	#8
	8. People could not truly understand how I feel about my cancer diagnosis.	0.77	
3: Expecting that others will not understand existential thoughts.	4. People would not understand my thoughts about death since my cancer diagnosis.	0.75	#10
	10. People would not understand my uncertainty about the future since my cancer diagnosis.	0.78	
4: Expecting sharing cancer-related concerns to burden others.	3. If I shared my concerns about cancer with people then it would be too hard on them.	0.69	#9
	9. I would burden people if I shared my thoughts and feelings about cancer with them.	0.76	
5: Expecting telling others about their diagnosis or cancer-related concerns to change their relationship for the worse.	6. If I told people about my cancer experience, they would be nervous and uncomfortable around me.	0.79	#6
	12. If I told people about my cancer experience, our relationship would change for the worse.	0.57	
	14. If I shared my concerns about cancer with people then they might hurt me with their reactions.	0.64	

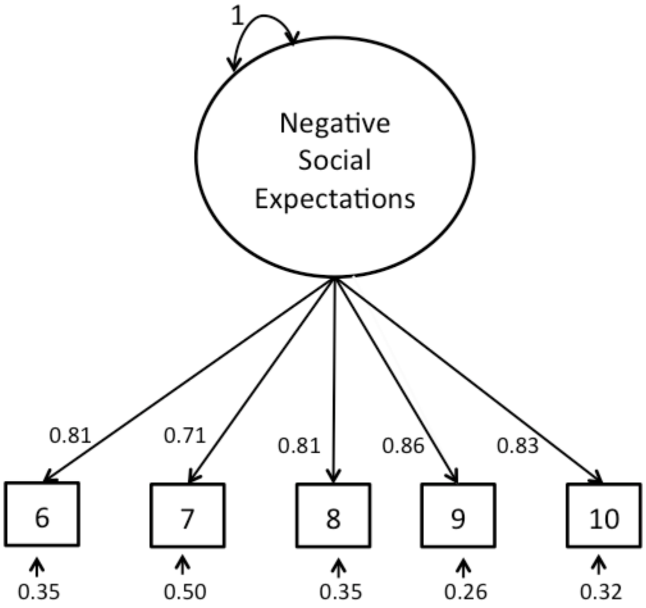

Figure P10.

Test of the Final Cancer-related Negative Social Expectations Scale Model

Table P12.

Correlations for Assessment of Construct Validity

	Cancer-related Loneliness	Cancer-related Negative Social Expectations
Cancer-related Negative Social Expectations	—	0.70**
Emotional Support	-0.66**	-0.48**
Depression	0.54**	0.41**
Anxiety	0.55**	0.41**
Pain	0.50**	0.36**
Fatigue	0.45**	0.39**
Sleep Disturbance	0.51**	0.43**
Mental Quality of Life	-0.54**	-0.43**
Physical Quality of Life (4-item)	-0.24**	-0.25**
Physical Quality of Life (3-item)	-0.33**	-0.31**
Social Constraints	0.80**	0.67**
General Loneliness	0.67**	0.47**
Num. Relatives	-0.12	—
Num. Relatives (winsorized)	0.41**	—
Num. Friends	-0.19*	—
Num. Friends (winsorized)	0.44**	—
Num. Coworkers (*n*=77)	0.26**	—
Num. Coworkers (*n*=77, winsorized)	-0.14	—
Num. Cancer Patients	-0.21**	—
Num. Cancer Patients (winsorized)	-0.14	—

Note. N=186 unless otherwise specified.
*$p < 0.05$. **$p < 0.01$.

VITA

VITA
REBECCA N ADAMS
March 2016

Current Positions

July 2015- Present	*Psychology Intern* Health and Behavior Track University of California Los Angeles- Semel Institute (APA-Accredited Clinical Psychology Internship Program)
August 2011- Present	*Ph.D. Student in Clinical Psychology* Indiana University-Purdue University Indianapolis Department of Psychology, Indianapolis, IN 46202

Education

December 2015	Dissertation defense:	*Measures of Cancer-related Loneliness and Negative Social Expectations: Development and Preliminary Validation*
	Chairperson:	Catherine E. Mosher, Ph.D.
	Committee:	Adam T. Hirsh, Ph.D., Kurt Kroenke, M.D., and Kevin L. Rand, Ph.D.
January 2014		*Admitted to Doctoral Candidacy*, Clinical Psychology Indiana University-Purdue University Indianapolis Department of Psychology, Indianapolis, IN 46202
May 2013	M.S.	*Clinical Psychology* Indiana University-Purdue University Indianapolis Department of Psychology, Indianapolis, IN 46202
	Thesis:	*Do Health Behaviors Mediate the Relationships between Loneliness and Health Outcomes in Caregivers of Cancer Patients?*

	Chairperson:	Catherine E. Mosher, Ph.D.
	Committee:	Adam T. Hirsh, Ph.D. and Kevin L. Rand, Ph.D.
August 2011		*Admitted to the Ph.D. Program in Clinical Psychology* (APA-Accredited Clinical Program) Indiana University-Purdue University Indianapolis Department of Psychology, Indianapolis, IN 46202
June 2010	B.S.	*Psychology (Magna Cum Laude)* Minor: Biology California Polytechnic State University, San Luis Obispo Department of Psychology and Child Development, San Luis Obispo, CA 93407
	Senior Project:	*Information Processing and Induced Mood*
	Project Advisor:	Jason A. Williams, Ph.D.

Professional Interests

- Psycho-oncology and cancer survivorship
- Family caregiving in cancer
- Psychosocial factors as they relate to health behaviors and health outcomes

Honors, Grants and Fellowships

May 2015	Victoria Champion Award for Outstanding Publication (awarded annually for an outstanding cancer-focused publication)
April 2015	IUPUI Clinical Psychology Research Excellence Award (awarded annually to one graduate student for research excellence)
November 2014	American Psychological Association (APA) Dissertation Research Award ($1000; research grant for doctoral dissertation)
August 2014	IUPUI Psychology Dissertation Scholarship ($1,000; scholarship for doctoral dissertation)
March 2014	IUPUI Clinical Psychology Program Research Funding Award ($1,295; research grant for doctoral dissertation)
August 2013-Present	National Cancer Institute R25 award. *Training in Research for Behavioral Oncology and Cancer Control.* R25-CA117865-06. Victoria L. Champion, Ph.D., RN, FAAN (PI). Role: Predoctoral Fellow. Primary mentor: Kurt Kroenke, M.D. Secondary mentors: Catherine E. Mosher, Ph.D. and Patrick Monahan, Ph.D.

March 2013	IUPUI School of Science Graduate School Council Travel Grant ($600; travel grant for Society of Behavioral Medicine 2013 conference)
March 2013	IUPUI Graduate and Professional Student Government Educational Enhancement Grant ($500; travel grant for Society of Behavioral Medicine 2013 conference)
August 2012-July 2013	IUPUI University Fellowship for academic achievement
April 2012	IUPUI Graduate and Professional Student Government Educational Enhancement Grant ($500; travel grant for Society of Behavioral Medicine 2012 conference)
August 2011-July 2012	IUPUI University Fellowship for academic achievement
December 2006-June 2010	California Polytechnic State University San Luis Obispo Dean's List

Peer Reviewed Publications

1. **Adams, R.N.**, Mosher, C.E., Cohee, A.A., Stump, T., Monahan, P., Sledge, G.W., Cella, D., & Champion, V.L. (in press). Avoidant coping and self-efficacy mediate relationships between perceived social constraints and symptoms among long-term breast cancer survivors. *Psycho-Oncology*.

2. Cohee, A.A., **Adams, R.N.**, Von Ah, D., Monahan, P., Zoppi, K., Fife, B.,…Champion, V.L. (in press). Relationship between depressive symptoms and social cognitive processing in partners of long-term breast cancer survivors. *Quality of Life Research.*

3. **Adams, R.N.**, Mosher, C.E., Abonour, R., Robertson, M.J., Champion, V.L., & Kroenke, K. (in press). Cognitive and situational precipitants of cancer patients' loneliness: A qualitative analysis. *Oncology Nursing Forum*.

4. Winger, J.G., **Adams, R.N.**, & Mosher, C.E. (2016). Relations of meaning in life and sense of coherence to distress in cancer patients: A meta-analysis. *Psycho-Oncology, 25*, 2-10. doi: 10.1002/pon.3798

5. Mosher, C.E., **Adams, R.N.**, Helft, P.R., O'Neil, B.H., Shahda, S., Rattray, N.A., & Champion, V.L. (2015). Family caregiving challenges in advanced colorectal cancer: Patient and caregiver perspectives. *Supportive Care in Cancer*. Advance online publication. doi: 10.1007/s00520-015-2995-z

6. Cohee, A.A., **Adams, R.N.**, Johns, S.A., Von Ah., D., Zoppi, K., Fife, B., . . . Champion, V.L. (2015). Fear of recurrence in long-term breast cancer survivors and partners. *Psycho-Oncology*. Advance online publication. doi: 10.1002/pon.4008

7. **Adams, R.N.**, Winger, J.G., & Mosher, C.E. (2015). A meta-analysis of the relationship between social constraints and distress in cancer patients. *Journal of Behavioral Medicine, 38,* 294-305. doi: 10.1007/s10865-014-9601-6

8. **Adams, R.N.**, Mosher, C.E., Blair, C.K., Snyder, D.C., Sloane, R., & Demark-Wahnefried, W. (2015). Cancer survivors' uptake and adherence in diet and exercise intervention trials: An integrative data analysis. *Cancer*, *121,* 77-83. doi: 10.1002/cncr.28978

9. **Adams, R.N.**, Mosher, C.E., Cannady, R.S., Lucette, A., & Kim, Y. (2014). Caregiving experiences predict changes in spiritual well-being among family caregivers of cancer patients. *Psycho-Oncology, 23,* 1178-1184. doi: 10.1002/pon.3558

10. Santoro, M.S., Van Liew, C., Cronan, T.A., Franks, H.M., **Adams, R.N.**, Roesch, S.C., Wooldridge, J.S., & Tomita, M. (2014). Physical function and quality of well-being in fibromyalgia: The applicability of the goodness-of fit hypothesis. *Health Psychology and Behavioral Medicine*, *2*, 496-508. doi: 10.1080/21642850.2014.905205

11. Santoro, M.S., Cronan, T.A., **Adams, R.N.**, & Kothari, D.J. (2012). The relationship between fibromyalgia and hysterectomy: The impact on health status and health care costs. *Clinical Rheumatology, 31*, 1585-1589. doi: 10.1007/s10067-012-2051-z

12. Franks, H.M., Cronan, T.A., Santoro, M.S., Roesch, S.C., Devos-Comby, L., Wooldridge, J.S., & **Adams, R.N.** (2012). Is coping goodness-of-fit related to depression and mood disturbance in women with fibromyalgia syndrome? *Journal of Musculoskeletal Pain, 20,* 183-193. doi: 10.3109/10582452.2012.704144

13. Freberg, K., **Adams, R.**, McGaughey, K., & Freberg, L. (2010). The rich get richer: Online and offline social connectivity predicts subjective loneliness. *Media Psychology Review, 3,* 103-115.

Manuscripts Submitted for Publication

14. Cohee, A.A., **Adams, R.N.**, Von Ah, D., Monahan, P., Zoppi, K., Fife, B.,…Champion, V.L. (under review). Relationship between depressive symptoms and social cognitive processing in partners of long-term breast cancer survivors.

Posters Presented at Scientific Meetings

With published abstract proceedings:

1. **Adams, R.N.**, Cohee, A.A., & Champion, V.L. (2015). The impact of social constraints from health providers on breast cancer survivors' symptom burden. Poster presented at the 2015 Society of Behavioral Medicine Annual Meeting, San Antonio, TX.

2. Winger, J.G., **Adams, R.N.**, & Mosher, C.E. (2015). Relations of meaning in life and sense of coherence to distress in cancer patients: A meta-analysis. Poster presented at the 2015 Society of Behavioral Medicine Annual Meeting, San Antonio, TX.

3. **Adams, R.N.**, Mosher, C.E., & Ostroff, J.S. (2013). Caregiving burden, alcohol use, smoking, and distress among family caregivers of lung cancer patients. *Annals of Behavioral Medicine, 45 s104.* Poster presented at the 2013 Society of Behavioral Medicine Annual Meeting, San Francisco, CA.

4. **Adams, R.N.**, Wooldridge, J.S., & Cronan, T.A. (2012). Does appraised risk and susceptibility mediate the relationship between health locus of control and intentions to be screened for CRC? *Annals of Behavioral Medicine, 43, s5*. Poster presented at the 2012 Society of Behavioral Medicine Annual Meeting, New Orleans, LA.

5. **Adams, R.**, Brown, K., Santoro, M., & Cronan, T. (2011). The effects of ethnicity and educational level on willingness to pay a health care advocate. *Annals of Behavioral Medicine, 41, s115.* Poster presented at the 2011 Society of Behavioral Medicine Annual Meeting, Washington D.C.

Without proceedings:
(*Student/Mentee work)

6. **Adams, R.N.** & Mosher, C.E. (2015). Cognitions related to cancer patients' loneliness: A qualitative analysis. Poster presented at the 2015 Association of Psychological Science Convention, New York, NY.

7. *Stout, M., **Adams, R.N.**, & Mosher, C.E. (2015). Associations between loneliness and cancer patients' pain and fatigue. Poster presented at the 2015 IUPUI Research Day, Indianapolis, IN.

8. **Adams, R.N.** & Mosher, C.E. (2014). The relationship between social constraints and distress among cancer patients: A meta-analysis. Poster presented at the 2014 Indiana University Simon Cancer Center Cancer Research Day, Indianapolis, IN.

9. **Adams, R.N.** & Mosher, C.E. (2014). The relationship between social constraints and distress among cancer patients: A meta-analysis. Poster presented at the 2014 Society of Behavioral Medicine Annual Meeting, Philadelphia, PA.

10. **Adams, R.N.**, Mosher, C.E., & Ostroff, J.S. (2013). Caregiving burden, alcohol use, smoking, and distress among family caregivers of lung cancer patients. Poster presented at the 2013 Indiana University Simon Cancer Center Cancer Research Day, Indianapolis, IN.

11. Freberg, K., **Adams, R.**, McGaughey, K., Blume, M., Werter, B., Menon, A. Rust, M., & Freberg, L. (2010). Leaders or snakes in suits: Perceptions of today's CEOs. Poster presented at the Association of Psychological Science Convention, Boston, MA.

12. Williams, J., Blume, M., & **Adams, R.** (2010). Uniform color affects attributions of success in sporting teams. Poster presented at the Association of Psychological Science Convention, Boston, MA.

13. Ainley, B., Freberg, K., **Adams, R.**, Enrique, C., & Freberg, L. (2009). Loneliness predicts perceptions and use of social networking sites. Poster presented at the Association of Psychological Science Convention, San Francisco, CA.

Membership in Professional Associations

2011-Present	Student member of the American Psychological Association, Division 38 (Health Psychology)
2010-Present	Student member of the Society of Behavioral Medicine
2008-2011; 2014-Present	Student member of the Association of Psychological Science
2008-Present	Psi Chi, the National Honor Society in Psychology

Editorial Activities: Mentored Ad Hoc Reviews

December 2015	*Palliative and Supportive Care*
November 2015	*Palliative and Supportive Care*
February 2015	*Journal of Behavioral Medicine*
October 2014	*Psycho-Oncology*
April 2014	*Journal of Pain and Symptom Management*
May 2013	*Psycho-Oncology*

February 2013	*Journal of Health Psychology*
May 2012	*Sex Roles*
August 2010	*Cyberpsychology, Behavior, and Social Networking*

Research Experience

August 2011-Present	*Graduate Research Assistant*	
	Indiana University-Purdue University Indianapolis, Behavioral Oncology Laboratory	
	Duties:	Screen cancer patients for study eligibility, consent patients at the Indiana University Simon Cancer Center, University Hospital, and VA, conduct phone assessments with study participants, supervise undergraduate students, review grant proposals, and assist with data analyses and manuscript preparation.
	Supervisor:	Catherine E. Mosher, Ph.D.
July 2010-July 2011	*Research Assistant*	
	San Diego State University, Health Outcome Studies Lab	
	Duties:	Trained and supervised the undergraduate RAs in data collection and input. Assisted in the preparation of a grant proposal for a healthcare intervention and co-authored manuscripts related to coping in fibromyalgia patients.
	Supervisor:	Terry A. Cronan, Ph.D.
June 2009-June 2010	*Senior Project Research Assistant*	
	California Polytechnic State University, San Luis Obispo, SLO Perception and Attention Lab	
	Duties:	Developed and conducted an original research study on mood and visual information processing. Created the protocol using SuperLab experimental software, scheduled/ran participants, analyzed data, and wrote final Senior Project paper.
	Supervisor:	Jason A. Williams, Ph.D.

October 2008-June 2010	*Undergraduate Research Assistant*	
	California Polytechnic State University, San Luis Obispo, Laura Freberg's Lab	
	Duties:	Assisted with data coding and input, questionnaire construction, interviewing participants, conducting Block's Q-sort, literature compilation, and manuscript preparation.
	Supervisor:	Laura A. Freberg, Ph.D.

Selected Workshops and Training Experiences in Research and Writing

September 2014	*Mediation, Moderation, and Conditional Process Analysis Workshop (2 days)* Andrew F. Hayes, Ph.D., Professor, The Ohio State University
June 2014	*Dyadic Data Analysis Workshop (5 days)* Deborah Kashy, Ph.D., Professor, Michigan State University
August 2013	*Introduction to Meta-analysis Workshop (3 days)* Noel Card, Ph.D., Associate Professor, University of Arizona
August 2013-June 2015	*Cancer Control Educational Series* Monthly lectures on research topics related to cancer prevention and control.
July 2013	*Writing from the Reader's Perspective* George D. Gopen, PhD., Professor Emeritus, Duke University
July 2013	*Grant Writers' Seminars and Workshops* David C. Morrison, Ph.D., Professor, University of Missouri Kansas City
August 2012	*Introduction to Structural Equation Modeling Workshop (3 days)* Gregory Hancock, Ph.D., Professor, University of Maryland
August 2011-June 2015	*Oncology Faculty Research Group* Attend monthly faculty research group meetings led by Victoria Champion, Ph.D., RN, FAAN. Attendees provide feedback on peers' research proposals and grant applications.

Clinical Experience

July 2015-Present

Psychology Intern (Health and Behavior)

UCLA Semel Institute for Neuroscience and Human Behavior, David Geffen School of Medicine at UCLA

Adult Consultation-Liaison Psychiatry Service (July 2015-Present)

Duties:	Field consultation requests, assess and diagnose medical patients with psychiatric comorbidities, develop treatment recommendations, document clinical impressions and convey them to the primary medical team, provide brief psychotherapeutic interventions.
Supervisors:	John Brooks, Ph.D., M.D. Jennifer Kruse, M.D. David Wellisch, Ph.D.

Revlon/UCLA Breast Center (July 2015-Present)

Duties:	Psychological assessment of women who are either recently diagnosed with breast cancer or at high-risk for breast cancer. Convey clinical impressions and treatment recommendations to the multi-disciplinary treatment team.
Supervisor:	David Wellisch, Ph.D.

Medical Psychology Assessment Center (July 2015-Present)

Duties:	Administer, score, and interpret a range of psychodiagnostic tests. Assist with clinical interviews, feedback sessions, and preparation of integrative reports for referring physicians.
Supervisors:	Marilyn Jacobs, Ph.D. Jeffrey Lulow, Ph.D. Delaney Thrasher, Ph.D.

January 2014-August 2014

Psychology Practicum Student

Richard L. Roudebush VA Medical Center

Duties:	Provided individual therapy to adult clients in integrated primary care setting. Documented clinical impressions and conveyed them to the Veterans' primary care physicians. Co-led Managing Overweight/Obese Veterans Everywhere (MOVE!) and

Pain Management groups. Administered, scored, and interpreted personality and neuropsychological assessments. Assisted with transplant evaluations and preparation of integrative reports.

Supervisor: Jennifer Chambers, Ph.D.

May 2013-December 2013 *Psychology Practicum Student*

Neuropsychology Clinic at Department of Psychiatry, Indiana University School of Medicine

Duties: Administered, scored, and interpreted a range of neuropsychological assessments. Assisted with clinical interviews, feedback sessions, and preparation of integrative reports for referring physicians.

Supervisor: Daniel Rexroth, Psy.D., HSPP

January 2013-May 2013 *Psychology Practicum Student*

Consultation-Liaison Psychiatry Service at Indiana University Health University Hospital, Department of Psychiatry, Indiana University School of Medicine

Duties: Fielded consultation requests, assessed and diagnosed medical patients with psychiatric comorbidities, developed treatment recommendations, documented clinical impressions and conveyed them to the primary medical team, provided psychotherapeutic interventions.

Supervisor: David Fingerhut, Ph.D., HSPP

August 2012-December 2012 *Psychology Practicum Student*

Larue D. Carter Memorial Hospital

Duties: Served as a clinician within adolescent female, adolescent male, and child inpatient state psychiatric units. Provided individual psychotherapy to individuals with mood, conduct, psychotic, and developmental disorders. Attended weekly supervision session, participated in team treatment

	meetings, and wrote clinical progress notes.
Supervisor:	John Spanke, Ph.D., HSPP

Selected Clinical Workshops and Training Experiences

September 2015-Present	*Advanced Neuropsychological Syndromes and Psychodiagnostic Seminar* Weekly seminar at UCLA Semel Institute in psychodiagnostic assessment, advanced interpretive strategies for evaluating a variety of complex neuropsychiatric conditions, and differential diagnosis of the most common neurological, general medical, and neuropsychiatric disorders that impact neuropsychological status, as well as disease pathophysiology.
July 2015-Present	*Psychology Intern Seminar* Weekly seminar at UCLA Semel Institute covering current topics in clinical psychology (e.g., psychopathology, diagnostic evaluation and modalities of treatment).
March 2015	*Acceptance and Commitment Therapy Workshop* Jennifer Lydon-Lam, Ph.D., Psychologist, Richard L. Roudebush VA Medical Center
April 2014	*Biofeedback Workshop* Eric Scott, Ph.D., Assistant Professor, Indiana University
April 2013	*Self-Hypnosis for Chronic Pain Management Workshop* Mark P. Jensen, Ph.D., Associate Professor, University of Washington
August 2012-June 2015	*Meta-Supervision* Attended monthly supervision meetings at IUPUI with students enrolled in practicum and a licensed clinical psychologist. Received supervision on clinical work and reported intervention progress. Received feedback on a transcribed therapy session. Received didactics and supervision on clinical peer supervision.
August 2011-June 2015	*Proseminar on Professional Issues in Clinical Psychology* Weekly professional development course at IUPUI covering advanced clinical topics such as case conference/case conceptualization and clinical practice issues. Relevant topics included: supervision, consulting, diversity, ethics, professionalism, teaching, research methods, licensure, and grant writing.

Teaching Experience and Training

September 2014-June 2015	*Undergraduate Research Mentor* Mentored an undergraduate research assistant for an independent study psychology research course.
September 2014	*Guest Lecturer: Undergraduate Introductory Psychology Course* Topic: Learning.
August 2012	*Seminar in Teaching Psychology* Learned best practices for undergraduate learning. Practiced course preparation by creating an undergraduate Abnormal Psychology course syllabus.
January 2011-May 2011	*Tutor* Led weekly group tutoring for advanced graduate-level statistics. Hired by the San Diego State Research Foundation to instruct minority undergraduate students in the NIMH-funded Career Opportunities in Research Program at San Diego State University.
October 2010- May 2011	*Instructor* Taught weekly preparation course for the Graduate Record Examination (GRE) Verbal subtest. Hired by the San Diego State Research Foundation to instruct minority undergraduate students in the NIMH-funded Career Opportunities in Research Program at San Diego State University.