2013

Role of Health Behaviors in Sexual Quality of Life Among Hematopoietic Stem Cell Transplant Survivors

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A Thesis Submitted in Partial Fulfillment of the

Requirements for the Degree of

Master of Arts

In

Clinical Psychology

Minnesota State University, Mankato

Mankato, Minnesota

May 2013

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Date defended: April 8, 2013

Acknowledgments

First thanks must go to my mentor, Dr. Eric Sprankle, as my accomplishments are direct results of his guidance and support. My growth as a professional (and as a person within that profession) would simply not have occurred, let alone been catalyzed in the manner that it has, without him. Dr. Christi Patten deserves infinite gratitude, as well, both as a member of my committee, and research supervisor whose guidance, support, and faith have challenged and helped me to reach my full potential in entirely new ways. I am very grateful for Dr. Kristie Campana's statistical support both overall and particularly with such a complex dataset—the insight I have gained from learning from her has made me a much more effective consumer and producer of science. Dr. Shawna Ehlers deserves special thanks for allowing me to utilize her dataset for this project, as well as being an excellent mentor and support in the time I have known her.

I must thank Dr. Patten's research team—Christine Hughes, Tabetha Brockman, Gail Bierbaum, Marcelo Hanza, Christina Smith, Dr. Shawna Ehlers, and Dr. Carrie Bronars—for their support and assistance throughout this process. Special thanks goes to Dr. Carrie Bronars for not only being an outstanding colleague, but for opening her home to me, as well as becoming a true and great friend whom I feel privileged to know.

I thank my parents, Henry and Darcy, and sister, Angela, for their support and grounding. I also thank the friends and classmates I have met in the past two years—Matt Schumann, Randi Bretz, Meghan Ecker Lyster, Alicia Kruger, Kristina Peltz, Sherry Werkmeister, and Morgan Page—for their support and friendship over the last two years. Finally, I must thank program faculty—Drs. Jeff Buchanan and Sarah Sifers—for their countless instances of instruction and unfailing support.

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Author's Note

This publication was made possible by CTSA Grant Number UL1 TR000135 from the National Center for Advancing Translational Sciences (NCATS), a component of the National Institutes of Health (NIH). Its contents are solely the responsibility of the authors and do not necessarily represent the official view of NIH.

Abstract

Hematopoietic stem cell transplant (HSCT) recipients are a population increasingly characterized by survivorship. A psychosocial outcome integral to overall quality of life and optimal survivorship outcomes is sexual quality of life (SQOL). In this arena, HSCT patients' prognostics are markedly grim. Though examinations of variables that affect overall survivorship in HSCT patients are relatively novel, SQOL outcomes have still received a disproportionately minimal amount of focus both in research and practice. Because health behaviors and their correlates are implicated in SQOL outcomes in the general population as well as survivorship and overall QOL outcomes in HSCT patients, inquiring about the relationship(s) between health behaviors and SQOL outcomes in HSCT patients is a logical next step in attempting to establish the etiologies of poor SQOL outcomes in order to ultimately improve HSCT survivors' outcomes longitudinally. The present study examines how health behaviors (exercise, diet, alcohol, and tobacco use) affect sexual interest and satisfaction in HSCT patients, and how correlates of health behaviors as well as adjunctive variables might contribute to those relationships. From these results, implications for research and practice are discussed, and utilized to make recommendations for future research and practice changes.

Introduction

Sexual Quality of Life Importance, Problems, & Associated Etiologies

Sexual quality of life (SQOL) is a major, central component of one's overall quality of life (QOL) such that the two are highly positively correlated. As a composite, macro-level construct, it is highly, independently predictive of one's QOL, and SQOL is strongly associated with longevity and happiness. This notion has been evidenced by a mass of individual studies (e.g., Carpenter, Andersen, Fowler, & Maxwell, 2009; Christensen, Grønbæk, Pedersen, Graugaard, & Frisch, 2011; Golbasi & Erenel, 2012; Haavio-Mannila & Kontula, 1997; Laumann, Paik, & Rosen, 1999; McCall-Hosenfeld et al., 2008; Neto & Pinto, 2012; Nusbaum & Hamilton, 2002; Read, King, & Watson, 1997; Thygesen, Schjødt, & Jarden, 2012; Ussher, Perz, & Gilbert, 2012) as well as internationally validated standardized measures such as the World Health Organization's Quality of Life Assessment (Skevington, Lofty, & O'Connell, 2004). SQOL encompasses many interrelated micro constructs, including objective measures (e.g., frequency, dysfunction [physiological or psychological]) and subjective assessments (e.g., interest, desire, satisfaction), as well as emotional and physical health components (Haavio-Mannila & Kontula, 1997). It can be affected by a wide range of factors, including (but not limited to) economic, intellectual, spiritual, and cultural values of the individual and the communities in which they exist, as well as emotional and physical support systems available to the individual (Golbasi & Erenel, 2012; Thygesen et al., 2012). Considering these relationships and the associated degree to which SQOL permeates different components of one's life, it should be no surprise that negative changes to SQOL have

many serious implications for health, emotional well-being, and QOL (Ussher et al., 2012).

Individuals who experience subjectively-assessed problems with their sex life (e.g., lack of interest, desire, and/or satisfaction; clinically significant psychological and somatic dysfunction) self-report their QOL and health-related QOL significantly more negatively (Ventegodt, 1998). This remains true when controlling for relevant variables such as age and physical functioning levels (Carpenter et al., 2009). Outside of pervasive, significant dysfunctions, perhaps the best metrics for indicating a need for intervention are subjective (Carpenter et al., 2009). Though intercourse frequency is often correlated with SQOL overall (Carpenter et al., 2009; Neto & Pinto, 2012), temporally-bound measurements of sexual activity cannot be used as an equitable substitute for measurements of SQOL; simply engaging in intercourse does not imply any inherent degree of satisfaction (Ussher et al., 2012).

SQOL problems and concerns may be resultant of a seemingly limitless range of factors. Sexual dysfunctions majorly affect SQOL and are largely prevalent in the general population, with point prevalence rates for both genders in the range of 50-60% at any given time (Laumann et al., 1999; Nusbaum & Hamilton, 2002; Read et al., 1997; Rosen, Taylor, Leiblum & Bachmann, 1993; Spector & Carey, 1990) not at all uncommon. Higher rates often present in different samples and settings—for example, primary medical care settings may evidence sexual dysfunction prevalence rates as high as 75% (Read et al., 1997). Sexual dysfunctions and subclinical issues are strongly associated

with poor physical and emotional sexual satisfaction, and are both independently and concomitantly predictive of poorer QOL outcomes (Laumann et al., 1999).

Independent and/or comorbid psychological disorder and distress contribute to an increased likelihood for sexual dysfunction and work concomitantly with existing SQOL-related issues to create significantly poorer QOL outcomes (Laumann et al., 1999; McCall-Hosenfeld et al., 2008; Nusbaum & Hamilton, 2002). These relationships may be further negatively affected by relatively peripheral factors (e.g., sexual self-schema; Carpenter et al., 2009). Further, treatments for common psychological disorders (e.g., selective serotonin reuptake inhibitors [SSRIs]) have a high propensity to independently affect SQOL negatively, as well. SSRIs, specifically, have been known to additionally create sexual functioning problems (McCall-Hosenfeld et al., 2008; Nusbaum & Hamilton, 2002).

Though marriage and partnered reproduction, as constructs, are increasingly less integral to SQOL (Haavio-Mannila & Kontula, 1997), relationship- and partner-related variables are major components of psychological well-being and therefore are still central to SQOL. Support from a significant other, particularly in the context of health or other major life issues, imparts significant positive influence on SQOL (Golbasi & Erenel, 2012). Simply having a partner with which one is engaged in a sexual relationship is associated with increased satisfaction, though it is important to note that not being in a sexual relationship with a partner is not similarly associated with negative SQOL (McCall-Hosenfeld et al., 2008; Neto & Pinto, 2012).

Sociodemographic variables, though comparatively less malleable, are still equally important to consider when it comes to predicting SQOL (Haavio-Mannila & Kontula, 1997). Age presents variable influences such that younger age is associated with increased reports of problems with SQOL (e.g., arousal difficulties; Carpenter et al., 2009) but increased reports of satisfaction (Haavio-Mannila & Kontula, 1997). Recent evidence suggests that, longitudinally, age-related differences are less pronounced than when explicitly comparing young individuals to all others and/or specific groups of older persons (Dunn, Croft, & Hackett, 2000; Neto & Pinto, 2012). Gender differences are often present in objective measurements of SQOL (Haavio-Mannila & Kontula, 1997), but are absent in self-reports of what, specifically, matters to one's SQOL (Haavio-Mannila & Kontula, 1997) and subjective satisfaction reports (Neto & Pinto, 2012). Age and gender often interact, however, to create unique complications that are less tentatively evidenced; for example, older males are more likely to experience arousal difficulties and lack desire (compared to younger males), whereas younger females are more likely to report sexual problems overall than older females (Laumann et al., 1999; McCall-Hosenfeld, 2008).

Race and ethnicity are, by comparison, more loosely associated with SQOL (relationships are presumed to be chiefly due to other adjunctive variables more directly associated with race/ethnicity), though some evidence has linked relatively more sexual problems with Black individuals and relatively fewer problems with Hispanic individuals (Laumann et al., 1999). Higher income rates have also been tentatively associated with more positive SQOL subjective reports (McCall-Hosenfeld et al., 2008). Finally,

education levels are often implicated in SQOL such that lower education levels are often associated with poorer SQOL (Carpenter et al., 2009; Laumann, Gagnon, Michael, & Michaels, 1994; McCall-Hosenfeld et al., 2008; Ojanlatva, Helenius, Rautava, Ahvenainen, & Koskenvuo, 2003), with differences being especially marked when comparing those without a high school diploma or equivalent to those with a college degree or more (Laumann et a., 1999). That being said, it is worthwhile to note that conflicting results regarding education's role in SQOL have been presented (e.g., Haavio-Mannila & Kontula, 1997; Myers & Diener, 1995; Neto & Pinto, 2012; Pavot & Diener, 1993).

In addition, physical health and associated behaviors play massive roles in SQOL. Health problems, major/chronic illnesses (e.g., cancer), weight (chiefly affected by diet, nutrition, and physical activity), alcohol use, and tobacco use have been implicated in SQOL in a multitude of ways, ranging from inactivity and associated dissatisfaction (Christensen et al., 2011; Nusbaum & Hamilton, 2002), overall dissatisfaction (regardless of activity level; McCall-Hosenfeld et al., 2008), and clinically significant sexual dysfunction (Christensen et al., 2011; Laumann et al., 1999). These relationships exist such that poor health behaviors and their resultant outcomes are positively associated with poor SQOL/increased risk of sexual dysfunction, but it is worthwhile to note that various examinations of some of these relationships have presented different results.

In particular, alcohol use's relationship with SQOL is variable. Treating alcohol use as a dichotomous variable (i.e., user versus non-user), McCall et al. (2008) found no effect on satisfaction. However, when other investigators have treated alcohol use as a

continuous variable, tentative associations between alcohol use and satisfaction have emerged such that only moderate to high use may not be associated with increased risk for dysfunction (Laumann et al., 1999). Further, though tobacco use's role in SQOL has been chiefly associated with erectile difficulties in males (Gades et al., 2005), Christensen et al. (2011) found tobacco use to negatively affect SQOL in women, as well. More, clearer examinations of these relationships are needed to determine tobacco's role in SQOL outcomes for all persons.

This illustrates a potential explanation for some of the tentative relationships between all said variables. Many of these factors may work together in unique ways to effect negative change in SQOL rather than predominantly doing so vacuously and/or completely independent of other variables. There is, therefore, a high likelihood that such factors are interrelated and work both independently (as illustrated above) and concomitantly to complicate SQOL outcomes. For example, women are particularly at risk for poor outcomes if they have had breast or gynecological cancers or are experiencing postmenopausal hormonal or other changes/complications, wherein relationship-related variables may also be of more importance to SQOL than in men (Ussher et al., 2012). As does QOL (Wilson & Cleary, 1995), SQOL subsumes a multitude of variables and their effects, such as genetic influences, clinical variables, and mental and physical health variables that cannot be completely separated and examined wholly distinctly.

Mental Health's Role in Quality of Life

Mental health and well-being are also vital components of one's QOL. Perhaps the clearest indicator of a lack of quality of life to any degree is a presence of psychological distress (whether sub-clinical symptoms or diagnosable disorders; e.g., depression, anxiety), though mental illness and the like also contribute to decreased QOL by affecting one's physical health, as well. Individuals with mental illness are prone to more negative health outcomes (e.g., increased risk for chronic illness [Colton & Manderschield, 2006]) and may die as much as 25 years earlier than those who do not experience mental health problems (Manderschield, Druss, & Freeman, 2007). Approximately 57.5 million individuals experience psychological distress and/or mental illness annually (National Alliance on Mental Illness [NAMI], 2009), and approximately 3.2% of the general population will have experienced serious levels of such problems in the last 30 days at any given point (National Center for Health Statistics & Centers for Disease Control [CDC], 2012). Thus, when assessing any component of one's QOL (such as SQOL), it is imperative to consider the potential role(s) of mental health and well-being.

Health Behaviors' Role in Quality of Life

Health behaviors (e.g., diet, exercise, substance use) are largely foretelling of one's QOL. Poor diet, a sedentary lifestyle, tobacco use, and excessive alcohol use are predictive of poorer life outcomes, and are among the most common behaviors for which healthcare professionals make recommendations for change (Amarantos, Martinez, & Dwyer, 2001; Fontaine & Barofsky, 2001; Hassan, Joshi, Madhavan, & Amonkar, 2003;

Kolotkin, Head, Hamilton, & Tse, 1995; Volk, Cantor, Steinbauer, & Cass, 1997; Wilson, Parsons, & Wakefield, 1999). As such, combinations of problematic behaviors therein place an individual at a remarkably heightened risk for poor quality of life.

Tobacco use causes the most preventable deaths in the United States (U.S. Department of Health and Human Services [USDHHS], 2004), preempts people to premature death (Centers for Disease Control and Prevention [CDC], 2002), and is a well-known cause of cancer (World Health Organization, 2007) and cardiovascular and respiratory diseases (CDC, 2008). Excessive alcohol use predisposes individuals to a wide range of immediate and long-term health risks, including injury (Smith, Branas, & Miller, 1999), violence (Greenfield, 1998), sexually transmitted infections (Naimi, Lipscomb, Brewer, & Colley, 2003), sexual violence (Wechsler, Davenport, Dowdall, Moeykens, & Castillo, 1994), cardiovascular issues (Rehm, Gmel, Sepos, & Trevisan, 2003), liver disease (Heron, 2007; Schiff, 1997), gastrointestinal issues (Kelly, Kaufman, Koff, Laszlo, Wilholm, & Shapiro, 1995; Lesher & Lee, 1989), cancer (Baan et al., 2007), psychiatric illness (Castaneda, Sussman, Westreich, Levy, & O'Malley, 1996), and neurological issues such as dementia and stroke (Corrao, Rubbiati, Zambon, & Arico, 2002; Corrao, Bagnardi, Zambon, & La Vecchia, 2004).

Poor diet and nutrition are also associated with heightened risks for serious illnesses (USDHHS & U.S. Department of Agriculture, 2005), and increased health-related and QOL (USDHHS, 2000). Regular exercise reduces one's risk of cardiovascular disease, diabetes, metabolic disorders, and cancers, in addition to strengthening bones and muscles (CDC, 2011). Diet and exercise work concomitantly to keep one at a healthy

body weight, and being overweight or obese is associated with an array of health issues, including cardiovascular disease, diabetes, cancer, stroke, liver disease, gallbladder disease, sleep apnea, respiratory problems, osteoarthritis, menstruation issues and infertility (CDC, 2011b). In addition, overweight and obesity are linked with negative social and interpersonal, mobility, self-esteem, sex life, and occupational outcomes (Kolotkin et al., 1995).

Hematopoietic Stem Cell Transplantation

Hematopoietic stem cell transplantation (HSCT) is a procedure by which individuals afflicted with hematologic malignancies receive transplanted, healthy cells from either blood or bone marrow (bone marrow transplantation [BMT]) that is either transplanted from healthy sites within their own body (autologous transplantation) or a healthy donor (allogeneic transplantation). Diseases for which HSCT may be an appropriate treatment chiefly include hematologic and lymphoid malignancies (e.g., leukemia, myeloma, lymphoma) but may also include autoimmune disorders, amyloidosis, anemias, myelodysplatic disorders, and myeloproliferative disorders (Copeland, 2006). Over 10,000 people receive HSCT each year, though these rates are consistently increasing (Center for International Blood & Marrow Transplant Research, 2011; Copeland, 2006).

A relatively new (though no longer experimental) procedure, HSCT patients have benefited greatly from advances in its science (Wu et al., 2012). As much as 20% annual increases in HSCT's utilization (Gooley et al., 2010) have undoubtedly contributed to consistently increasing survivorship rates. Depending upon various prognostic factors,

immediate (i.e., within the first year) survival probabilities are currently estimated as high as 80% (Center for Blood & Marrow Transplant Research, 2011), and 10-year survivorship has been reported at rates as high as 68.8% (Bhatia et al., 2005). Thus, it only follows that long-term outcomes and the factors that may affect them must receive increasing focus in order to enhance patient outcomes in an enduring fashion.

SQOL in HSCT recipients.

Hematopoietic stem cell transplantation (HSCT) recipients display markedly grim prognostic factors with respect to SQOL, and these and related concerns are some of the most common long-term issues in these patients (Thygesen et al., 2012). The negative effects of HSCT on SQOL are enduring, though other physiological and psychological effects of cancer and HSCT may wax and wane over time (Humphreys, Tallman, Almaier, & Barnette, 2007; Thygesen et al., 2012); this finding is consistent with those in other cancers and associated treatments (Golbasi & Erenel, 2012). By comparison, SQOL problems are pervasive such that HSCT patients report problems/dysfunction up to 7 times as much as the general population (Humphreys et al., 2007) and approximately half of HSCT patients are dissatisfied with their sex life post-transplant (Thygesen et al., 2012). SQOL problems persist as other majorly significant psychosocial issues and transitions (e.g., grieving, health sequelae, occupational issues, family concerns) appear *and* resolve (Molassiotis, 1997), are present in significantly higher numbers at 10 years post-transplant (Thygesen et al., 2012), and worsen over time, particularly when such problems are left unaddressed/-treated (Humphreys et al., 2007; Thygesen et al., 2012).

The intense nature of HSCT treatment and resulting complications likely contribute to these problems (Thygesen et al., 2012). One of the most notable complications is graft-versus-host-disease (GVHD), which significantly impacts sexual functioning and associated QOL in those whom it afflicts (Copeland, 2006; Thygesen et al., 2012). GVHD presents in allogeneic patients as a result of the healthy, transplanted cells recognizing the healthy cells within the recipient's body as "foreign" and subsequently attacking them as the body might otherwise attack an infection. GVHD's effects on sexual functioning include (but are not limited to) complications such as vaginal stenosis (narrowing of the vagina due to scar tissue buildup), rash, increased skin sensitivity, and inflammation of skin near genital areas (Thygesen et al., 2012). Other treatment sequelae, such as hair loss, muscle loss, skin rashes/dryness/sensitivity, scars, edema, induced menopause [and associated hormone replacement therapy (HRT)], functional limitations, and infertility are highly likely to affect SQOL, as well (Thygesen et al., 2012). Further, many requirements of treatment (e.g., chemotherapy, medications) are highly likely to have an impact on sexual health, functioning, and associated QOL (Thygesen et al., 2012) via inherent toxicities.

Health behaviors' role in HSCT.

Reduction and/or cessation of problematic health behaviors are nearly universal recommendations made to patients undergoing HSCT (Bishop et al., 2010). Lack of regular physical activity, excess body weight, and associated complications (i.e., obesity, diabetes, etc.), as well as tobacco use and excessive alcohol use are risk factors for cancer occurrence and recurrence in addition to cancer patients' inherently increased

susceptibility to having cancer again, reduced QOL, poor physical functioning, pain, hypertension, cardiovascular disease, fatigue, and more contributors to poor outcomes (Bishop et al., 2010; Courneya, Katzmarzyk, & Bacon, 2007; Denmark-Wahnefried, Aziz, Rowland, & Pinto, 2005). Considering the abovementioned ways in which such health behaviors affect SQOL in the general population, such contraindicating factors for optimal HSCT outcomes may therefore complicate SQOL in HSCT recipients both independently and through direct effects on HSCT outcomes. This potential etiological factor for poor SQOL becomes more pronounced when one considers that several studies (e.g., Bishop et al., 2010 & Courneya et al., 2007) have evidenced that, despite their increased contact with healthcare providers and the salience of the "teachable moment" (Bishop et al., 2010; Denmark-Wahnefried et al., 2005) provided by a cancer diagnosis, HSCT recipients are by no means more likely (and, in some cases, are less likely) to engage in healthy behaviors or associated behavior change than the general population. Bishop et al. go on to report that as few as 20% of HSCT patients' providers discuss health behaviors with patients (of whom 10% self report actually recalling such discussions with providers).

Mental health's role in HSCT.

Psychiatric comorbidity and psychological distress/disorder are, too, of dual concern in this context. Such comorbidity is present in as much as 50% of cancer patients overall, and may contribute to a variety of negative outcomes such as increased mortality/shorter survival, increased illness severity, and treatment noncompliance (which independently predicts negative outcomes; Akaho et al., 2003; Beanlands et al.,

2003; Bunzel & Laederach-Hofmann, 2000; Khan, Irfan, Shamsi, & Hussain, 2007; Miovic & Block, 2007; Nakahara et al., 2002; Watson, Haviland, Greer, Davidson, & Bliss, 1999). Though early, methodologically-limited studies (e.g., Broers, Hengeveld, Kaptein, Cessie, van de Loo, & de Vries, 1998; Chang, Orav, Tong, & Antin, 2004; Chang, Orav, McNamara, Tong, & Antin, 2004; Hengeveld, Houtman, & Zwaan, 1988; Hoodin, Uberti, Lynch, Steele & Ratanatharathorn, 2006; Jenkins, Lester, Alexander, & Whittaker, 1994; Murphy, Jenkins, & Whittaker, 1996) suggested these relationships were tentative in HSCT recipients [see Dew, Switzer, DiMartini, Matukaitis, Fitzgerald, & Kormos (2000) for a broad review], more recent, stronger investigations have evidenced the tremendous importance of psychological variables in HSCT recipients' outcomes (both short- and long-term; Olbrisch, Benedict, Ashe, & Levenson, 2002) such that they are equally necessary to consider as other clinical variables.

Similar to population estimates for cancer patients overall, poor psychological well-being factors (e.g., anxiety, fear, hopelessness, guilt, irritability, sleep loss, hallucinations, confusion, hopelessness, and helplessness) have been noted in as much as 50% of HSCT patients (Khan et al., 2007). Due to the paucity of research on the topic and wide variability in pre-transplant assessments (Olbrisch et al., 2002), reported rates of Axis I diagnoses in HSCT patients vary widely, from 37.5% to 54% when reported dichotomously (i.e., present or not present; Jenkins, Linington, & Whittaker, 1991; Khan et al., 2007; Kirsh, McGrew, Dugan, & Passik, 2004; Leigh, Wilson, Burns, & Clark; Prieto et al., 2005b; Sasaki, Akaho, Sakamaki, & Akiyama, 2000). Reports of individual diagnoses range from adjustment disorder, to depressive disorders, to anxiety disorders,

to substance use issues, and "acute confusional states" (Khan et al., 2007; Kirsh, McGrew, Dugan, & Passik, 2004; Miovic & Block, 2007; Prieto et al., 2002), though these diagnoses are significantly more reliable than when examining psychiatric comorbidity as a dichotomous variable (Khan et al., 2007; Kirsh, McGrew, Dugan, & Passik (2004); Miovic & Block, 2007; Prieto et al., 2002). Further, it is important to note that acute confusional states are specifically related to HSCT treatment, hence their common presence as a comorbid diagnosis in this population (Khan et al., 2007).

Specifically, fear- and apathy-based factors such as hopelessness and helplessness are positively associated with the degree of the malignancy's intrusiveness (Beanlands et al., 2003). Anxiety, anger, and hostility are particularly predictive of a patient's noncompliance with treatment regimens (Bunzel & Laederach-Hoffman, 2000), and depression (whether warranting a clinical diagnosis or not) strongly predicts poor QOL outcomes (Colón, Callies, Popkin, & McGlave, 1991) and mortality (Prieto et al., 2005a). Conversely, lesser depressive symptomology has been confirmed as a significant predictor of better outcomes (Hoodin, Kalbfleisch, Thornton, & Ratanatharathorn, 2004), and protective psychological factors (e.g., optimism) predict better outcomes even when controlling for other health-related variables (Lee, Loberiza, Rizzo, Soiffer, Antin, & Weeks, 2003). Particular to SQOL, Humphreys et al. (2007) found pre-transplant depression to be associated with clinically significant sexual dysfunction up to 3 years post-transplant. Thygesen and colleagues' (2012) substantial review of the existing literature examining HSCT's impact on sexuality illustrates that body image concerns, anxiety, depression, self-confidence/-esteem issues, fatigue, stress and emotional distress,

among other such issues are widespread in HSCT patients and implicated in reciprocal relationships with both QOL and SQOL.

Providers' role in HSCT patients' SQOL outcomes.

One of the most troubling yet *completely* preventable complicating factors central to HSCT recipient SQOL outcomes is the lack of provider investment in HSCT recipients' SQOL. At least half of HSCT patients report that at no point during the treatment process did their providers discuss SQOL matters with them (Humphreys et al., 2007). The likelihood that this is a conservative estimate is high (Thygesen et al., 2012), as the lack of providers' discussion of sexual topics in other cancers and medicine overall is widespread. For example, Ussher et al. (2012) found that only 25% of their participants (breast cancer patients) had providers who discussed sexual well-being with them, though the likelihood for SQOL complications in breast cancer patients is one of the highest in all of medicine.

Additionally troubling is physicians' open acknowledgement of the dissonance of their practices herein, chiefly resultant of personal discomfort or lack of adequate information (as indicated by self-report; Read et al., 1997). Though it is widely known that simply taking a patient's sexual health history (not specific to any particular assessment or intervention) can significantly contribute to decreased prevalence rates and associated complications, providers who constantly underestimate sexual problems' prevalence fail to take such a history (Nusbaum & Hamilton, 2002). In Stead, Brown, Fallowfield, and Selby (2003), 98% of 43 providers treating individuals with ovarian cancer acknowledged the importance of SQOL outcomes and reported feeling that sexual

issues need to be discussed with patients, but only 21% of them reported actually doing so. Nusbaum and Hamilton (2002) similarly reported that a maximum of 35% of physicians self-report discussing sexual matters with patients at least 75% of the time, though when physicians do so, reports of problems have been known to increase by up to 6 times as much (Bachmann, Leiblum & Grill, 1989). This further indicates there is a clear and substantial need that physicians are failing to address. In Read and colleagues' (1997) examination, though 75% of patients felt it appropriate for providers to discuss sexual matters with patients, just 2% of all sampled providers had any notes related to sexual health, functioning, or well-being in patients' files, and the 25 most severely affected patients had no notes from their providers in their medical records acknowledging (let alone addressing) the problem(s).

Integration of Background Information

The potential interactions of all of the aforementioned factors have the necessary capacity to significantly and pervasively affect an HSCT recipient's SQOL, therefore circumventing the attainment of optimal post-transplant QOL and potentially contributing to unnecessary complications. Concurrently, the pronounced lack of provider investment in HSCT recipients' sexual well-being translates to a dearth of research on the topic via clinical avoidance that produces a lack of data and information with which to conduct such needed research. As a result, HSCT survivors are experiencing documented significantly more negative outcomes with respect to their sexual well-being, and there is little awareness as to the complete etiology of these outcomes. This lack of knowledge continues to exacerbate providers' feelings of apprehension and as though they are not

well-equipped to handle such issues, which continues to cause problematic clinical avoidance, and so on.

The purpose of the present study was to examine SQOL in HSCT survivors (i.e., patients 1 year post-transplant) in order to understand important correlates and predictors of both problematic and satisfactory outcomes. More specifically, health behaviors and demographic factors as predictors and moderators (respectively), as well as treatment-related and mental health variables as mediators and covariates, were of interest. As illustrated above, these variables likely both work independently and concomitantly to determine some portion of SQOL (and therefore overall QOL) outcomes. Knowledge regarding the nature of these relationships may contribute to the development of better assessment and intervention protocols for such patients, in turn positively affecting HSCT survivors' QOL.

Aims and Hypotheses

Primary aim 1.

The first primary aim was to examine health behaviors may predict SQOL outcomes in HSCT survivors who are 1 year post-transplant. Within this aim, there were two hypotheses. Consistent with the extant literature, the first hypothesis was that current tobacco use, not meeting U.S. Public Health Service guidelines for physical activity, and physicians' recommendations for behavior change and subsequent non-adherence would predict lower self-reported SQOL. The second hypothesis was that alcohol use and diet/nutrition may significantly affect SQOL. These two variables have presented mixed

results with respect to affecting SQOL; accordingly, exploratory analyses were to be conducted.

Primary aim 2.

The second primary aim was to identify associated covariates, mediating, and/or moderating variables in the relationship(s) between SQOL and health behaviors examined in the first primary aim. There were three hypotheses herein. The first hypothesis was that demographic variables (i.e., gender, age, education level, relationship status) would moderate the strength of the relationships in the first primary aim and associated hypotheses in manners consistent with extant literature and the general population (while considering the treatment context via controlling for treatment covariates). The second hypothesis was that mental health-related variables (specifically, depression, anxiety, body image, and overall psychological functioning) would mediate the strength of the aforementioned relationships such that more adverse mental health outcomes would work with unhealthy behaviors to predict poor SQOL outcomes. Finally, the third hypothesis was that transplant-related treatment variables (i.e., transplant type, pain, fertility, would exist as covariates significant to the aforementioned relationships. See Figure 1 for theoretical visual representation of these aims and hypotheses in a composite, moderated mediation model (with covariation) according to Preacher, Rucker, and Hayes (2007).

Methods

Participants

Participants in the present study were patients who (a) received HSCT at an academic medical center in Southeastern Minnesota, (b) consented to participate in the primary study, (c) and completed and returned both the pre- and post-transplant lifestyle survey as of August 15, 2012 (N = 469). This date was chosen as a cutoff date for the purposes of seeking institutional approval for the present study. The present study falls under the umbrella of the primary study, for which institutional approval was obtained from Mayo Clinic on January 20, 2009 (see Appendix A). Additional institutional approval for the present study was obtained from Minnesota State University, Mankato on October 3, 2012 (see Appendix B), as well as inter-institution permission for data utilization (see Appendix C).

In order to be included in the primary study (which primarily focuses on health behaviors' roles in HSCT survivorship and broad psychosocial outcomes), patients must have been (a) at least 18 years of age, (b) void of a current psychotic or neurological disorder that may have precluded participation, (c) fluent in the English language, (d) referred by an HSCT provider at Mayo Clinic within the context of their multidisciplinary pre-transplant evaluation, and (e) provided written informed consent to participate in the study. Participants in the present study received HSCT between June 29, 2009 and October 7, 2011. Most individuals received autologous transplantation (n = 374; 79.74%), and were receiving treatment for plasma cell disorders (excluding amyloid; n = 197; 42.83%) or non-Hodgkin's lymphoma (n = 102; 22.17%). Participants

were primarily Caucasian (n = 427; 91.04%), male (n = 264; 56.29%), married (legally recognized or otherwise; n = 377; 80.38%), and between 40 and 65 years of age (n = 324; 69.08%). Most were employed (n = 195; 41.58%) or retired (n = 115; 24.52%), with highest education levels relatively equally split between those with some college or a 2-year degree (n = 141; 30.06%), a 4-year degree (n = 102; 18.98%), or post-graduate studies (n = 100; 21.32%). See Table 1 for complete demographic and diagnostic characteristics.

It is important to note that due to the archival nature of this study, participants' right to refuse to answer any questions, and the need to pair readily available data with clinically abstracted data (not under the purview of the principal investigator for the primary study or therefore necessarily available for research purposes), availability of data was limited in some cases. As a result, sample size varies depending upon the variable(s) of interest in a given analysis (see Tables 2 and 3 for sample sizes dependent upon each health behavior question and Table 4 for sample sizes and longitudinal analyses of primary criteria). In some cases, this significantly reduced the power of proposed statistical inferences. In these instances, there were not enough data to utilize standard analyses or bootstrapping procedures in a manner that would allow sufficiently utilizable results, so analyses were forgone.

Procedures

Prior to transplantation, patients were required to undergo a tertiary care pre-transplant psychological evaluation (unless medically contraindicated) in the form of a semi-structured interview completed by a Masters-level therapist and supervised by a

licensed doctoral-level psychologist. As a part of this assessment, patients completed two clinical survey packets composed of standardized items such as the Brief Fatigue Inventory (Mendoza et al., 1999), Beck Depression Inventory (BDI-II; Beck, Steer, Ball, & Ranieri, 1996), State-Trait Anxiety Inventory (STAI; Spielberger, Reheiser, Ritterband, Sydeman, & Unger, 1995), State-Trait Anger Expression Inventory (STAXI; Spielberger, Jacobs, Russell, & Crane, 1983), Functional Assessment of Cancer Treatment-General (FACT-G; Cella et al., 1993), Multidimensional Health Locus of Control (MHLOC; Wallston, 2004) measure, Big Five Inventory (BFI; John, Donahue, & Kentle, 1991), Eastern Cooperative Oncology Group Performance Status Scale (ECOG; Oken et al., 1982), COPE Inventory (Carver, Scheier, & Weintraub, 1989), and standard single self-report items (e.g., pain indication; see Appendices D and E for these assessment packets). Global assessment of functioning (GAF) scores were also obtained during this evaluation according to the *Diagnostic and Statistical Manual of Mental Disorders*'s [*DSM-IV-TR*; American Psychiatric Association (APA), 2000] guidelines (see Appendix F).

At the time of this evaluation, patients were informed of the nature of the primary study and were offered the opportunity to provide informed consent for participation (see Appendix G). After consenting to participate in the study, participants additionally completed the Lifestyle Survey for Transplant Patients (Pre-Transplant; see Appendix H). The Lifestyle Survey assessed health behaviors (i.e., nutrition, exercise/physical activity, tobacco and alcohol use) and related social support variables, using standardized measures or items from standardized measures such as the Stanford Exercise Behaviors

Scale, Question Inventory for Tobacco (QIT), and Alcohol Use Disorders Identification Test (AUDIT; Reinter & Allen, 2002). Survivors were mailed a novel version of the Lifestyle Survey approximately 1-year post-transplant (see Appendix I), which was modified to include additional items assessing quality-of-life variables (many of which were previously assessed in the separate pre-transplant standard clinical surveys).

For the purposes of the present study, data from portions of the pre-transplant clinical surveys, as well as both Lifestyle Surveys (pre- and post-transplant) were utilized for analyses. Namely, the Stanford Exercise Behaviors Scale (Lorig, Stewart, Ritter, González, Laurent, & Lynch, 1996), AUDIT, BDI-II, and STAI were utilized to assess exercise behaviors, alcohol use, and psychiatric distress (in the form of depressed mood and anxiety), respectively. Tobacco use was analyzed using items from the QIT. Global Assessment of Functioning (GAF) and functional status (ECOG) scores obtained during pre-transplant assessments were also used to assess functioning in a continuous and standardized fashion. Individual standardized questions assessing pain, diet/nutrition, body image, fertility concerns, current health, perception of treatment effects, and QOL were used to assess their respective constructs. Individual items from the FACT-G and BDI-II were additionally selected to assess SQOL specifically.

Psychometric Properties of Utilized Measures

The Stanford Exercise Behaviors scale is a one-item measure that asks the respondent to indicate the approximate number of minutes they spent on five different exercise behaviors (i.e., stretching/strengthening, walking, swimming, bicycling, and other) in the past 7 days. For the purposes of this study, time spent on

stretching/strengthening was excluded from calculations of aerobic activity. This scale has demonstrated appropriate item-total correlations without item overlap. This, in combination with its brevity and ease of administration, makes it an appropriate assessment tool for this population and sample (Lorig et al., 1996).

The QIT is a database of more than 6000 standardized questions assessing tobacco use indexed and maintained by the CDC. Each question has been obtained from established measures assessing tobacco use. See the pre- and post-transplant Lifestyle Surveys (Appendices G and H) for questions utilized for the purposes of the larger study and the present study specifically.

The FACT-G is a brief yet sensitive measure assessing quality of life variables in cancer patients across five main domains (physical well-being, social/family well-being, relationship with doctor, emotional well-being, and functional well-being). This measure has repeatedly demonstrated excellent convergent and divergent validity across subscales, sensitivity to longitudinal patient change (of particular importance in the present study), and test-retest reliability (with subscale coefficients ranging from .82 to .92; Cella et al., 1993).

The AUDIT is a free, simple, easy-to-administer, easy-to-score, and useful measure assessing alcohol use as a problematic variable in health care contexts. It has demonstrated sensitivity, reliability, and validity that meets or exceeds standards in a multitude of settings and lacks cultural bias across applications. Its focus on current behavior is a particular strength in the present sample and most health care populations (Reinter & Allen, 2002).

The BDI-II is a widely used measure assessing depression severity (Beck et al., 1996). It has been validated in a number of contexts and populations, including primary care medical settings. It has excellent psychometric properties overall (Beck et al., 1996), which have been echoed in validation studies in primary care (most relevant to the present study; Arnau, Meagher, Norris, & Bramson, 2001). Arnau et al. (2001) evidenced internal consistency of $\alpha = .94$, item-total correlations from .54 to .74, as well as excellent convergent and criterion-related validity.

The STAI is a theoretically and methodologically sound self-report scale assessing the degree to which anxiety is a product of a particular moment (state anxiety) juxtaposed against an individual's inherent propensity to experience anxiety (trait anxiety). Levitt (1967) has posited this instrument as the most intentionally developed instrument for these constructs, and it has been validated and utilized in a wide range of populations and contexts. The STAI demonstrates satisfactory validity and reliability, and by analyzing items from both scales that demonstrate respectively high content saturation, meaningful differentiating variables may be extrapolated (Ramaniah, Franzen, & Schill, 1983) regarding a person's experience of anxiety.

The GAF scale [Axis V of the *DSM-IV-TR* (APA, 2000)] is a standardized scale assessing a person's overall functioning within diagnostic contexts. There is well-established inter-rater reliability and convergent and discriminant validity amongst both clinicians and trained laypersons (Hilsenroth et al., 2000). The GAF scale is one of the most standardized diagnostic metrics one may use to assess a person's psychological well-being both overall and with respect to functional impairment.

Results

The present study utilized archival data in a retrospective within-subjects design. Primary modes of analyses were linear regression and analysis of variance (ANOVA) models depending upon suitability (i.e., regressions were utilized when predictors could be considered as continuous, while ANOVAs were utilized when predictors were categorical). Variations upon those models (e.g., multiple regression, hierarchical regression, MANOVA, ANCOVA, MANCOVA) were utilized in order to control for covariates and in mediation or moderation models.

While the proposed overall model required utilization of a moderated mediation model according to Preacher et al. (2007; see Figure 1), already mentioned limitations resultant of lacking casewise data circumvented the appropriateness and thorough utilization of this model. Further, the primary goal of this study was to describe SQOL in HSCT survivors—accordingly, utilizing such a model wherein all mediating and moderating data (much of which is notably susceptible to longitudinal change, particularly in this context) were acquired prior to transplant (while outcomes are post-transplant) would present convoluted results discordant with this purpose. As a result, moderation and mediation analyses were conducted individually to allow more accurate interpretations of results and their associated limitations.

Longitudinal Analyses and Continuity of Primary Variables

Patients in this sample self-reported their sexual satisfaction and interest in sex to be low at both measurements. Less than half (47.40%) indicated they were “quite a bit” or “very much” satisfied with their sex life pre-transplant, and much fewer (34.00%)

indicated so post-transplant. Pre-transplant sexual satisfaction significantly positively predicted post-transplant sexual satisfaction [$\beta = .373$, $R^2 = .14$, $F\ (1, 65) = 10.50$, $p = .002$].

Prior to transplant, half ($n = 77$; 51.30%) of all patients indicated that there had been no recent change in their interest in sex, 29.30% ($n = 44$) indicated a slight recent loss of interest in sex, 10.70% ($n = 16$) indicated a significant recent loss of interest in sex, and 8.70% ($n = 13$) reported they had, recently, completely lost all interest in sex. Post-transplant, less than one-third (31.00%) indicated they were at least "quite a bit" or "very much" interested in sex. Those who reported a greater recent loss of interest at the time of their pre-transplant psychological assessment reported significantly lower levels of interest post-transplant [$\beta = -.318$, $F\ (1, 139) = 15.66$, $p < .001$], implying the staying power of losses of sexual interest in this context.

There was not a significant relationship between pre-transplant sexual satisfaction and recent losses of interest in sex [$\beta = -.075$, $F\ (1, 3) = .017$, $p = .904$], though inferences from an analysis so lacking in statistical inference power should be interpreted with substantial caution. Additionally, irrespective of power issues, the coefficient in this case is remarkably weak, allowing even less room for inference. However, pre-transplant sexual satisfaction positively predicted post-transplant interest in sex [$\beta = .230$, $F\ (1, 76) = 4.24$, $p < .05$], and post-transplant interest in sex significantly positively predicted post-transplant sexual satisfaction [$\beta = .310$, $F\ (1, 350) = 37.27$, $p < .001$]. Finally, those who reported greater losses of interest in sex pre-transplant reported significantly lower levels of sexual satisfaction post-transplant [$\beta = -.347$, $F\ (1, 107) = 14.66$, $p < .001$]. This

indicates that, though all variables considered here are interrelated, a loss of interest in sex prior to transplant is likely caused by factors other than a lack of sexual satisfaction. See Table 4 for longitudinal relationships between variables and response rates. See Table 5 for numeric values assigned to response options (i.e., dummy-coding) for all analyses in the present study, and Table 6 for acronyms assigned to variables when reporting data in Tables 7-42.

Having established that (a) pre-transplant SQOL variables are strongly predictive of post-transplant SQOL and (b) it appears there is a notable propensity for SQOL prognoses therein to be bleak and indicate worsening of SQOL, it is important to note that pre-transplant casewise data (i.e., having both SQOL variables answered and/or all health behavior variables answered) was lacking to the degree that making accurate predictions regarding pre-transplant SQOL with sufficient statistical power was not possible (as noted in one of the above analyses). Further, the purpose of this study was to examine various factors that may affect SQOL 1 year after receiving the transplant. As a result, all following analyses predicting interest in sex or satisfaction with one's sex life represent post-transplant outcomes. Accordingly, it is important to note that most pre-transplant health behaviors were positively predictive of post-transplant health behaviors (see Table 7), though, again, lacking casewise data may limit interpretations of some of these relationships.

Notably, all metrics of SQOL (both pre- and post-transplant) significantly predicted post-transplant QOL (a metric not obtained in a single self-report measure pre-transplant). Greater pre-transplant sexual satisfaction [$\beta = .315$, $F\ (1, 76) = 8.36$, $p < .01$],

little to no loss of sexual interest pre-transplant [$\beta = -.203$, $F\ (1, 147) = 6.29$, $p < .05$], greater post-transplant sexual satisfaction [$\beta = .243$, $F\ (1, 354) = 22.23$, $p < .001$], and greater post-transplant sexual interest [$\beta = .268$, $F\ (1, 449) = 34.80$, $p < .001$] predicted greater QOL post-transplant. This emphatically confirms the known importance of optimal SQOL in QOL in the present sample.

Primary Aim 1

The primary purpose of this study was to examine the role of health behaviors in SQOL outcomes in HSCT recipients. As such, primary analyses examined the roles of exercise, diet/nutrition, tobacco, and alcohol use in participants' interest in sex and satisfaction with their sex lives. All analyses within primary aim 1 utilized individual linear regression analyses; due to wide variability in measurement scales used to assess predictors, standardized regression coefficients are reported for ease of interpretation.

Preliminary analyses.

Pre-transplant health behaviors' (previously established as indicative of post-transplant health behaviors) predictions of post-transplant SQOL outcomes were examined to provide an accurate baseline as possible. The only pre-transplant health behavior significantly indicative of post-transplant sexual satisfaction was post-diagnosis changes in exercise. Persons who reported increasing the amount of aerobic exercise in which they regularly engaged in the time since their diagnosis reported significantly greater sexual satisfaction. Increased tobacco use (as well as receiving direction to quit tobacco) positively predicted sexual satisfaction in a manner approaching significance, as well.

Pre-transplant health behaviors were comparatively more indicative of post-transplant interest in sex. Current tobacco users reported greater degrees of sexual interest in a manner approximating significance. Those who drank more regularly in the last year and reported increasing alcohol use since their diagnosis reported significantly greater interest in sex [though one must note that the vast majority (86.90%) of participants report alcohol use well within CDC guidelines]. In addition, those who met CDC guidelines for fruit and vegetable consumption and those who reported gaining weight since their diagnosis reported significantly greater degrees of interest in sex post-transplant. See Tables 8 and 9 for all predictions of post-transplant SQOL using pre-transplant health-related variables.

Primary analyses.

After receiving and surviving the transplant, those who received directions from healthcare providers in the last year to exercise more and/or eat better reported significantly lower levels of sexual satisfaction. Though not statistically significant, two other exercise-related variables evidenced comparatively low probabilities, and in a manner confirmatory of the importance of exercise in SQOL post-transplant. Those who increased the degree to which they engage in regular exercise and those who followed healthcare provider recommendations to exercise more in the year since their transplant reported higher levels of sexual satisfaction. Vegetable intake also positively predicted sexual satisfaction, suggesting that overall nutrition plays an important role in sexual satisfaction post-transplant (though rendered statistically insignificant by fruit intake,

which did not play as much of a role). See Table 10 for all predictions of sexual satisfaction post-transplant.

Several health behaviors significantly predicted the degree to which one reported they were interested in sex at 1-year post transplant, as well. Aerobic exercise—both continuously and dichotomized according to CDC guidelines (i.e., at least 150 minutes per week)—positively predicted higher rates of sexual interest. Confirming the importance of exercise, receiving healthcare provider recommendations to exercise more significantly predicted lower reports of sexual satisfaction. Further, those who increased their rates of exercise post-transplant reported significantly higher sexual satisfaction, and those who reported both receiving that recommendation and subsequently following it reported significantly higher sexual satisfaction than those who were told to exercise more but did not heed the advisement.

Healthy eating habits also played an important role in interest in sex post-transplant. Approaching statistical significance (with a comparatively very low probability), it appears that those who received a recommendation to eat more healthily reported much lower rates of sexual interest. Corroborating this notion, those who reported increasing their healthy eating habits post-diagnosis and -transplant also reported significantly higher rates of sexual interest.

Substance use played considerable roles in interest in sex post-transplant. Trichotomized (i.e., current vs. former vs. never) tobacco use predicted interest in sex in a manner approaching significance (with a much lower comparative probability than most other predictors) such that more recent use predicted lower rates of sexual interest.

Regularity of alcohol use in the last year significantly positively predicted post-transplant interest in sex, though it is worthwhile to note that typical consumption rates did not significantly predict interest (suggesting the importance of longitudinal patterns versus cross-sectional assessments of alcohol consumption). See Table 11 for all predictions of interest in sex post-transplant.

Primary Aim 2

The second primary aim of the present study was to more clearly understand the relationships that emerged in the first primary aim. Specifically, researchers believed that sociodemographic, psychological well-being, and HSCT treatment-related variables would serve as moderators, mediators, and covariates, respectively. In light of aforementioned rationale for foregoing an otherwise most-appropriate moderated mediation analyses, individual moderation, mediation, and covariation models were utilized. This allows for the best possible interpretation of individual relationships' variability in this situation. Interpreting this variability in a compounded manner, as would occur in a moderated mediation model, using the present data should be left to the individual with proper clinical experience to do so.

Sociodemographic moderation analyses.

Two different methods were used to assess moderators depending upon the nature of the independent variable in question. When the independent variable was categorical (e.g., receiving healthcare provider recommendations for behavior change, or in instances where an otherwise continuous variable was placed into categories (e.g., trichotomized tobacco use, dichotomized total exercise according to CDC guidelines, or dichotomized

fruit and vegetable intake according to CDC guidelines), a factorial ANOVA was utilized wherein the interaction effect evidenced moderation. When the independent variable was continuous, independent regression coefficients from each group (i.e., male and female) were tested for significant differences using a *t*-test as described in Baron and Kenny (1986). It is also important to note that moderation analyses were only executed for primary analyses (concordant with the aim of this investigation)—that is, preliminary analyses utilizing pre-transplant variables as predictors were not assessed for moderation.

Gender.

Gender moderated many relationships between health behaviors and SQOL variables 1 year post-transplant. Examining satisfaction with one's sex life, gender significantly moderated the predictive abilities of alcohol consumption in the last year; typical drinking day alcohol consumption; and post-diagnosis and –transplant changes in healthy eating habits, weight, and alcohol consumption. Females overall and males who maintained or increased healthy food intake reported relatively constant levels of sexual satisfaction, but males who decreased healthy food intake reported significantly lower sexual satisfaction. Females who lost weight reported the highest satisfaction with their sex lives, followed by those who maintained their weight, followed by those who gained weight, while both males who gained and lost weight reported much lower sexual satisfaction than those who maintained since the time of diagnosis. Both genders reported highest levels of sexual satisfaction when alcohol use was either very sparse or very regular, with sexual satisfaction levels dropping in interim levels. Males who drank more

alcohol on a typical drinking day reported higher satisfaction with their sex lives, while the direct opposite was true for females.

Gender also moderated predictions of post-transplant interest in sex. Affected predictors were post-diagnosis and –transplant changes in healthy eating habits. Females who ate more healthily reported greater rates of interest in sex, while males who decreased healthy food intake reported decreased sexual interest (though maintaining or increasing intake were nearly identical, and following healthcare provider recommendations did not produce noticeable differences in males). See Tables 12 through 15 for data illustrating gender as a moderator of all primary relationships.

Partnership status.

Partnership status (dichotomized as either partnered or not partnered), oft-posited as a key (sometimes sole) determinant of many SQOL outcomes, moderated far fewer relationships. Partnership served as a significant moderator for the relationship between total fruit and vegetable intake and sexual satisfaction, and sub-significantly moderated the relationship between adherence to recommendations to eat more healthily and sexual satisfaction. With respect to fruit and vegetable intake, partnership status did not appear to matter in individuals who were not meeting guidelines for fruit and vegetable intake, but meeting such guidelines was associated with much lower sexual satisfaction in non-partnered individuals and much higher sexual satisfaction in partnered individuals. Partnered individuals' satisfaction with their sex lives was not affected by whether or not they followed recommendations to eat better, whereas following such directions corresponded with much lower sexual satisfaction in non-partnered individuals.

Predicting post-transplant interest in sex, partnership status significantly moderated the predictive ability of post-diagnosis and –transplant changes in tobacco use and that of receiving recommendations to gain weight, in addition to sub-significantly moderating the predictive ability of receiving recommendations to reduce alcohol use. Partnered individuals who increased tobacco use, and did not receive recommendations to gain weight or reduce alcohol use reported the highest rates of sexual interest compared to other categories within those variables. Non-partnered individuals who did not use or maintained tobacco use, received recommendations to gain weight, and were told to reduce alcohol use reported the highest rates of interest in sex compared to similar non-partnered individuals. See Tables 14 through 17 for data illustrating partnership status as a moderator of all primary relationships.

Education level.

Education level significantly moderated predictions of sexual satisfaction post-transplant. Affected factors were receiving recommendations to eat more healthily and adherence to recommendations to quit tobacco. Those with a high school education were the only individuals to report lower satisfaction with their sex lives when they did not receive directions to eat more healthily, and the difference between a 2- and 4-year college education produced an interaction effect such that those with a 4-year college degree reported much lower sexual satisfaction when they did not follow recommendations to quit tobacco (the direct opposite was true for those with a 2-year degree).

With respect to interest in sex, the only moderated relationship was that initially determined by receiving recommendations to reduce alcohol use. The determinant of this moderation is likely that those with a high school diploma or GED reported markedly higher interest in sex if they were directed to reduce alcohol use; all other combinations of variables were relatively constant based on education level. Education's moderation of the predictive ability of post-diagnosis and –transplant changes in exercise approached significance, as well. The determinant of this moderation is likely the marked increase in sexual interest reported by those with less than an 8th grade education reporting decreasing exercise post-diagnosis; and upward trend in sexual interest corresponded with increases in exercise for all other education levels. See Tables 18 and 19 for data illustrating education as a moderator of all primary relationships.

Age.

Age, too, served as a moderator of post-transplant SQOL variables. Though age did not moderate any predictions of interest in sex, age moderated the predictive abilities of behavioral adherence to recommendations to exercise more and gain weight with respect to sexual satisfaction. Individuals aged 19-40 years reported sharp increases in satisfaction with their sex lives when they followed recommendations to eat better and lose weight, while such relationships were comparatively of a much smaller magnitude for other age groups. See Tables 20 and 21 for data illustrating age as a moderator of all primary relationships.

Psychological well-being mediation analyses.

Mediation analyses were executed using hierarchical multiple regressions for all models. Once again, mediation analyses were only executed for primary analyses (i.e., using post-transplant health behaviors to predict post-transplant SQOL variables). Because mental health variables were assessed pre-transplant, and because we do not have data regarding these variables (save for participant's approval of the appearance of their body) post-transplant, these analyses must be interpreted with appropriate caution. Concurrently, it is important to note that clinically significant distress and dysfunction is unlikely to completely disappear with one year, health behaviors largely did not change over time, and SQOL variables predicted themselves from pre- to post-transplant—thus, while these results should be interpreted with a certain degree of caution, they are likely still indicative of important relationships.

Depression.

Predicting interest in sex, depression fully mediated trichotomized tobacco use; aerobic exercise (both continuously and dichotomized according to CDC guidelines); healthcare provider recommendations for increased exercise, increased healthy food intake, and alcohol use reduction; post-diagnosis and –transplant changes in healthy eating, and total fruit and vegetable intake. Depression partially mediated post-diagnosis and –transplant changes in exercise and alcohol intake, as well as adherence to recommendations to exercise more and typical alcohol consumption in the last year. Mediated models accounted for 5-9% more variance than non-mediated models. All mediation relationships existed such that greater degrees of depression were indicative of

lower interest in sex. See Table 22 for data illustrating depression as a mediator of these health behavior variables post-transplant.

Predicting satisfaction with one's sex life, depression fully mediated all otherwise significant predictors. These were healthcare provider recommendations to exercise more and eat better, post-diagnosis and –transplant changes in exercise (and, therefore, adherence to recommendations to exercise more), typical alcohol consumption in the last year, and total fruit and vegetable intake. Mediated models accounted for 13-15% more variance than non-mediated models. All mediation relationships existed such that greater degrees of depression were indicative of lower satisfaction with one's sex life. See Table 23 for data illustrating depression as a mediator of these health behavior variables post-transplant.

Anxiety.

State anxiety did not mediate any relationships potentially subject to mediation. Trait anxiety did not mediate post-transplant sexual satisfaction, though it did mediate several predictors of post-transplant interest in sex. Trait anxiety fully mediated trichotomized tobacco use; aerobic exercise (both continuously and dichotomized according to CDC guidelines); healthcare provider recommendations for increased exercise, healthy food intake, and alcohol use reduction; post-diagnosis and –transplant changes in healthy eating, and total fruit and vegetable intake. Trait anxiety partially mediated post-diagnosis and –transplant changes in exercise and alcohol intake, as well as adherence to recommendations to exercise more and typical alcohol consumption in the last year. Mediated models accounted for 3-5% more variance than non-mediated

models. See Table 24 for data illustrating trait anxiety as a mediator of these health behavior variables post-transplant.

Global functioning.

GAF scores did not mediate post-transplant interest in sex, but fully mediated all predictions of post-transplant sexual satisfaction. These were healthcare provider recommendations to exercise more and eat better, post-diagnosis and –transplant changes in exercise (and, therefore, adherence to recommendations to exercise more), typical alcohol consumption in the last year, and total fruit and vegetable intake. Mediated models accounted for 5-9% more variance than non-mediated models. See Table 25 for data illustrating GAF scores as mediators of these health behavior variables post-transplant.

Body image.

With respect to interest in sex, participant's approval of the appearance of their own body (assessed post-transplant, unlike other mediators) fully mediated the predictive abilities of trichotomized tobacco use, healthcare provider recommendations to exercise more and eat more healthily, and total fruit and vegetable intake. Body image (as defined here by self-report of approval of body appearance; see Appendix I) partially mediated exercise (both continuously and dichotomized according to CDC guidelines), healthcare provider recommendations to reduce alcohol use, typical alcohol consumption in the last year, and post-diagnosis and –transplant changes in exercise, healthy eating, alcohol use, and adherence to recommendations to exercise more. Mediated models accounted for 4-

8% more variance than non-mediated models. See Table 26 for data illustrating depression as a mediator of these health behavior variables post-transplant.

Body image also fully mediated all predictions of post-transplant sexual satisfaction. These were healthcare provider recommendations to exercise more and eat better, post-diagnosis and –transplant changes in exercise (and, therefore, adherence to recommendations to exercise more), typical alcohol consumption in the last year, and total fruit and vegetable intake. Mediated models accounted for 12-13% more variance than non-mediated models. See Table 27 for data illustrating depression as a mediator of these health behavior variables post-transplant.

Treatment-related covariation analyses.

In trying to understand how health behaviors might affect SQOL in HSCT survivors, it is clearly paramount to place investigations of every relationship within the context of the illness and its treatment. While endless factors could affect any prediction of an outcome, several key variables often widely varying in HSCT and hugely capable of affecting anyone's SQOL were considered as covariates in the current investigation. These variables were patients' post-transplant reports of pain, concerns about fertility, QOL, overall current health, and treatment effects' being worse than expected. Other covariates as indicated by healthcare professionals were transplant type and functional status (ECOG; as reported within the immediate timeframe of transplant). Parsing out covariates was accomplished using hierarchical regression models (with continuous predictors) and analyses of covariance ([ANCOVAs] with categorical factors).

Instances in which controlling for treatment-related variables removed the significance of previously significant predictors of SQOL outcomes indicated that those health behaviors may not otherwise be important in determining SQOL outcomes for these patients, but the interaction between those health behaviors and the HSCT treatment context produced a unique catalyst for certain SQOL outcomes. When controlling for treatment-related variables introduced significance into a previously non-significant relationship between a health behavior and SQOL outcome, this elucidated that a potentially actually significant determinant of SQOL outcomes for these patients might be clouded by the treatment context. More explicit analyses of these sorts of relationships are ripe for future research to determine how health behaviors may interact with the treatment context to produce unique predictors of SQOL outcomes.

Transplant type.

Controlling for transplant type removed all significance of previously significant predictors of satisfaction with one's sex life. This control introduced significance into relationships between sexual satisfaction and regularity of alcohol use as well as fruit and vegetable consumption. See Table 29 for these analyses. Controlling for transplant type did not affect previously significant predictors of interest in sex and did not introduce significance into any previously non-significant health behaviors as predictors of interest in sex. See Table 36 for these analyses.

Pain.

Controlling for pain removed all significance of previously significant predictors of satisfaction with one's sex life. This control introduced significance into relationships

between sexual satisfaction and regularity of alcohol use as well as post-diagnosis changes in exercise. See Table 30 for these analyses. Controlling for pain did not affect previously significant predictors of interest in sex, but introduced significance into the relationships between interest in sex and aerobic exercise (measured continuously) and regularity of alcohol use. See Table 37 for these analyses.

Fertility concerns.

Controlling for fertility concerns removed all significance of previously significant predictors of satisfaction with one's sex life. This control introduced significance into relationships between sexual satisfaction and post-diagnosis changes in exercise. See Table 31 for these analyses. Controlling for fertility concerns did not affect previously significant predictors of interest in sex, but introduced significance into the relationships between interest in sex and aerobic exercise (measured continuously) and regularity of alcohol use. See Table 38 for these analyses.

Functional status.

Controlling for functional status removed all significance of previously significant predictors of satisfaction with one's sex life. This control introduced significance into relationships between sexual satisfaction and post-diagnosis changes in weight. See Table 32 for these analyses. Controlling for functional status removed previously established significance of dichotomized aerobic exercise, as well as healthcare recommendations to increase aerobic exercise and reduce alcohol use as predictors of interest in sex. This control did not remove the significance of any other previously established significant predictors of interest in sex, but introduced significance into the relationship between

interest in sex and adhering to recommendations to lose weight. See Table 39 for these analyses.

Overall QOL.

Controlling for overall QOL removed all significance of previously significant predictors of satisfaction with one's sex life. This control introduced significance into relationships between sexual satisfaction and tobacco use, aerobic exercise, regularity of alcohol use, typical drinking day alcohol consumption, and fruit and vegetable consumption. See Table 33 for these analyses. Controlling for overall QOL removed previously established significance of post-diagnosis changes in exercise as a predictor of interest in sex. This control did not remove the significance of any other previously established significant predictors of interest in sex, but introduced significance into the relationship between interest in sex and aerobic exercise (measured continuously) as well as regularity of alcohol use. See Table 40 for these analyses.

Post-transplant overall health.

Controlling for overall health removed all significance of previously significant predictors of satisfaction with one's sex life. This control introduced significance into relationships between sexual satisfaction and tobacco use, aerobic exercise, regularity of alcohol use, typical drinking day alcohol consumption, and fruit and vegetable consumption. See Table 34 for these analyses. Controlling for post-transplant overall health removed previously established significance of post-diagnosis changes in exercise and healthcare provider recommendations to exercise more as predictors of interest in sex. This control did not remove the significance of any other previously established

significant predictors of interest in sex, but introduced significance into the relationship between interest in sex and aerobic exercise (measured continuously) as well as regularity of alcohol use. See Table 41 for these analyses.

Treatment effects' being worse than expected.

Controlling for worsened treatment effects removed all significance of previously significant predictors of satisfaction with one's sex life. This control introduced significance into relationships between sexual satisfaction and tobacco use, aerobic exercise, regularity of alcohol use, fruit and vegetable consumption, and post-diagnosis changes in exercise. See Table 35 for these analyses. Controlling for worsened treatment effects did not affect previously significant predictors of interest in sex, but introduced significance into the relationships between interest in sex and tobacco use, aerobic exercise (measured continuously), and regularity of alcohol use. See Table 42 for these analyses.

Discussion

The present study describes health behavior-related variables and associated sexual quality of life (SQOL) outcomes in a cohort of HSCT survivors. Only roughly half of respondents indicated being satisfied with their sex lives and/or not recently losing interest in sex prior to transplant, and only approximately one-third reported being satisfied with or interested in sex after surviving transplantation. Measurements of SQOL pre-transplant were very significantly predictive of SQOL post-transplant (which, if changing, was most likely to worsen), as were measurements of health behaviors over

time. Further, individuals who reported better SQOL were significantly more likely to report a better quality of life (QOL) overall.

Though preliminary analyses appeared to suggest that healthy behaviors are hardly related to greater SQOL post-transplant (particularly with respect to tobacco use, where current use predicted greater interest in sex), most of these relationships disappeared using post-transplant health behavior predictors, and/or were comparatively less indicative than such examinations. Further, it is imperative to consider the context in attempting to understand why these relationships might change over time or exist in the first place. Many of the examined behaviors often represent long-standing habits and/or addictive behaviors, and HSCT follows pre-transplant assessments relatively quickly. This means that prospective analyses utilize a period in which patients have not had sufficient opportunities to make very difficult health behavior changes. Additionally, there may not have been sufficient motive to do so—patients were likely functional for most intents and purposes, and prior to their diagnosis had likely not been provided with as salient a motive as a cancer diagnosis. Thus, any suggestion of causal or otherwise necessary links between pre-transplant behaviors and post-transplant outcomes must be quelled pending further investigation.

Cross-sectional examinations of post-transplant health behaviors and SQOL nonetheless went on to wholly disconfirm any notions that subpar or unhealthy behaviors were indicative of better SQOL in HSCT survivors or that health behaviors were relatively unrelated to such outcomes. In fact, these analyses indicated that, in general, the healthier a person's behaviors were, and the more they adhered to recommendations

to engage in healthier behaviors, the better their SQOL was. While moderating sociodemographic variables sometimes determined the importance of health behaviors in SQOL for a specific type of person, combinations of unhealthy behaviors and mediating mental health-related variables elucidated situations in which SQOL is at an incredibly increased risk for detriment in an already tenuous situation. Individuals who do not engage in healthy behaviors and are concurrently experiencing psychological distress and/or dysfunction are increasingly likely to experience poor SQOL outcomes.

Certainly the likelihood that simple, directly causal pathways exist in any of the examined contexts is low given the nature of these data and analyses, and even less likely in this population due to the context of the illness. However, the intent of this study was not to suggest causality. Rather, it was to contribute to a budding literature base addressing the need to improve long-term outcomes in HSCT recipients, most notably the comparatively malnourished literature base examining SQOL in these patients.

As established in prior research, this study evidenced that most HSCT patients experience poor SQOL both prior to transplant and after transplant. How a patient rates his or her SQOL prior to transplant likely indicates how he or she will rate it after transplant, and many experience a worsening of this very important part of their lives over time. Indeed, SQOL was strongly predictive of overall QOL in this sample, indicating that health behaviors, SQOL, and overall QOL are very much inter-related. Further, controlling for treatment-related variables in analyses evidenced that, outside of being pervasively functionally limited, being an HSCT patient does not affect a person's interest in sex, but it absolutely affects a person's satisfaction with their sex life.

While an opposing argument would likely juxtapose the life-or-death immediacy of the many needs of a cancer patient against the potential respective impact of a satisfactory sex life, this is predominantly why the primary focus of the present study was on *survivorship* outcomes. In HSCT patients, reaching the stage of survivorship is comparatively a novel concept, and as much information as possible is needed to understand how survivorship outcomes may be improved. A person experiencing problems with their sex life is much more likely to have a lower overall QOL, therefore preventing optimal survivorship outcomes (potentially in more ways than one). Additionally, extant literature indicates that such problems do not improve over time—in fact, they are very likely to worsen, or at least remain consistently poor.

Further, one must ask that providers juxtapose their definition of the word *surviving* with patients', caregivers', family members', and others' definitions of the word and what that means for themselves and their loved ones. Though many factors other than SQOL-related variables are very directly related to whether or not one does or does not die after the transplant, the likelihood that patients, the general population, and likely most practitioners would define *surviving* as *not being deceased* is negligible. There are clearly a multitude of factors that, while not directly related to not dying after the transplant, are still integral to *survivorship* and living a quality life as a survivor. The quality of one's sex life is without a doubt a huge component of any person's overall QOL, and it is evident that this remains true for HSCT patients.

There is a need for intervention that is not being effectively addressed, resulting in lasting, poor outcomes for patients already in a very delicate situation and who need as

few complications as possible. Though little is known about the exact nature of sexual problems in the present sample or the population overall, one may speculate that potential interventions may be implemented with ease relative to other oft-employed interventions such as tobacco cessation or improving diet and exercise. In one study, simply having a provider willing to discuss sexual issues with patients strongly predicted significantly better and enduring SQOL outcomes, suggesting that perhaps simply discussing sexually-related issues lends itself to much better outcomes (Nusbaum & Hamilton, 2002).

Unfortunately, most providers do not discuss sexually-related matters at an appropriate length (if at all) with their patients. Most feel they either do not have the expertise to do so, or simply feel embarrassed. However, patients look to their healthcare providers for expertise and assistance, and by not directly addressing such topics with patients, providers send the message that these matters are not important and that patients' concerns therein are not important. Additionally, this negligence of such an important topic circumvents opportunities for affected patients to vent their concerns about a matter regarding which they might not otherwise have the opportunity to receive help.

These problems in addressing sexual health are not unique to this context; avoidance of sexual topics and admitted dissonance between beliefs about the importance of sexual health and actual practice is widespread among almost all types of providers. Additionally indicative of attitudes dismissive of the importance of sexual health is the fact that widely utilized standardized measures such as the FACT-G provide additional options for refusal when it comes to answering questions about sexual behavior. Any

other standardized questions or measures carry the assumption that if a participant does not wish to answer or participate, they may simply not answer. However, the FACT-G offers additional, active options for refusal for sexually-related questions. While this was conceived in an effort to be sensitive to patients, it is important to remember that if a patient is already sensitive about a particular issue, it is imperative to thoroughly think through the language one uses to discuss such matters with patients; in fact, thoroughly considering vernacular use when discussing matters related to sexuality is paramount to better outcomes. An already sensitive patient prone to not wanting to discuss a sensitive issue is more likely to interpret an added indicator that they do not have to answer a particular question as a sign that the information to be obtained via that question is not important as compared to other questions, though it undoubtedly is in this case and all others.

To provide a comparison, an overweight or obese patient may be embarrassed about their weight, but that does not mean providers should communicate that knowing their weight is not important and subsequently ignore the potential associated outcomes of not addressing the issue. Combine this lack of equity in approach to sexual health with a patient who is experiencing trouble with that area of their life, in a culture that actively avoids addressing sexual health topics, and it is guaranteed that one will (a) not receive data necessary to research or practice, and (b) not address the needs of the patient. These consequences lend themselves to poor and worsening patient outcomes. Though socially normative in many contexts (as it might be to not discuss weight or age), this avoidance of sexually-related matters for reasons not based in therapeutic or empirical logic are

proving to be clinically harmful in more ways than one. Chief to the concerns of this study, it necessarily circumvents collecting data necessary to both understanding the etiologies of poor SQOL (and therefore overall QOL) outcomes and working to improve those outcomes, indirectly ensuring that such poor outcomes will continue to persist.

Future Directions

These results outline directions for future research and potential changes in practice. First and foremost, a clear solution to many problems herein is for healthcare providers to actively address and discuss sexual issues with patients. Even if providers feel ill-equipped to handle concerns with which patients may present (which is not necessarily supported by available evidence), they may consult outside expertise as they would with any other concern. Further, if providers feel they lack the necessary capabilities to address patient needs in this arena, they could approach the matter as they might any other lack in expertise, through continuing education and gaining expertise.

Providers may utilize the results of the present study and other existing literature to understand that if a patient presents prior to transplant indicating they have recently loss interest in sex or are, at that time, currently dissatisfied with their sex life, they should address these issues with the patient before such problems are given all too many opportunities to worsen. Additionally, particularly within the HSCT context, there are many complicated factors which may exacerbate or even create poor SQOL outcomes, and providers should be aware of how these factors may affect patients' sex lives and inform the patient accordingly, rather than risk letting the patient being blindsided without preparation. Such factors likely include treatment complications (e.g., graft-

versus-host disease), fatigue, pain, psychological issues, relationship variables resultant of having one's partner as a caregiver, and health behaviors.

The relationships outlined in the present study may also provide further impetus for behavior change that providers can communicate to patients. Though improving health behaviors is considered integral to optimal HSCT patient outcomes, and though a cancer diagnosis is presumed to provide a patient with a "teachable moment" for behavior change not otherwise afforded by other situations, HSCT patients by and large do not make significant, needed changes in their health behaviors. The reasons for this lack of change are likely multifaceted and very complicated, but the present study evidences that improving one's sexual quality of life after transplant is predicted by increasing one's engagement in healthy behaviors, and these outcomes may serve as an additional, and likely very salient, impetus for health behavior change.

Future research would be well-served to be specifically designed for these purposes in order capture variability in all variables (whether predictors, mediators/moderators/covariates, or criteria) as precisely as possible, as well. This includes both objective and subjective measures of SQOL outcomes, as well as self-report and verifiable (e.g., biologic) measures of health behaviors). Though experimental designs are not possible, HSCT treatment teams may work to ensure measures, assessments, and interventions are well-suited to collect specific data necessary to conduct statistical analyses sophisticated enough to untangle the aforementioned complicated relationships, and that these assessment and intervention protocols are uniformly implemented.

Limitations

There are several limitations to consider with respect to this study. Primarily, the nature of archival data lends itself to several significant limitations, the greatest of which is that the primary study for which data was collected was not specifically designed to assess SQOL variables. As a result, it is impossible to capture and assess variability in these outcomes in the best manner possible.

The self-report nature of the primary study, though it provides many benefits, also imposes many limitations on the present study. Though self-assessment of sexual satisfaction is undoubtedly an excellent metric of a very important outcome and very difficult to measure objectively, a person's sexual health and quality of their sex life can undoubtedly be measured in many more ways beyond interest and satisfaction (e.g., clinical diagnostics, sexual frequency, sexual functioning), and those measurements were unavailable for this study. Also, the additional provided option for participants' refusal to indicate how satisfied they are with their sex life imposed significant compounded limitations on the ability to assess variability in patients' SQOL. Confirming this limitation is the fact that individuals who refused to indicate how satisfied they were with their sex lives were significantly less interested than those who complied [$\beta = -.27$, F (1, 447) = 34.88, $p < .001$]. Those who refused to answer pre-transplant were most likely to refuse to answer post-transplant [$\beta = .34$, F (1, 168) = 21.29, $p < .001$].

Further, questions assessing a participant's interest in sex varied from pre- to post-transplant such that pre-transplant assessments were phrased (as all other questions in the BDI-II) with respect to *recent losses* (in interest in sex, in this case), while post-

transplant assessments of interest in sex were phrased with respect to interest in sex overall, disallowing direct comparisons between pre- and post-transplant measurements of interest in sex. Additionally, the likely intercorrelation between BDI-II totals and responses to the single BDI-II item (number 21) assessing recent losses of interest in sex was another reason why prospective analyses were not best suited for the goal of the present study.

Similarly, and also resultant of the archival nature of this study and its lack of design for the specified purpose of the present study, the limitation of measures and response options available to participants disallows capturing variability in health behaviors. For example, assessments of recent tobacco use included response options such as "8 days to 6 months ago" which clusters very different people and behaviors into the same group. That is, an individual who has not used tobacco in 6 months is very different in many ways (both objective and subjective) than one who used tobacco just over a week prior. Additionally, the self-report nature of the measures often lent itself to responses inconsistent with clinical cutoffs for behavior categories. For example, "former" tobacco uses were classified as individuals who had at one point used tobacco, but did not use tobacco within the last year. However, many individuals who were not classified as former tobacco users (i.e., they used within the last year) considered themselves to be non-users for other questions with response options such as "I am not a tobacco user." Biologic measures (e.g., cotinine analyses) confirm that as much as twice as many patients than those who indicate tobacco use via self-report are *actually* tobacco users (Ehlers et al., 2013).

This leads to limitations associated with self-report data. While self-report data certainly has its advantages, social desirability and other influences may circumvent honest responding, particularly with respect to health behaviors and sexual health-related variables. This may be increasingly true in this context, where health behaviors are paramount to certain treatment outcomes, and when patients may be under the impression that acknowledging they are engaging in unhealthy behaviors might affect their eligibility for treatment (though this is not necessarily accurate). More objective data (e.g., biomarkers for tobacco use, such as inflammatory marker assessment or cotinine analyses) would be especially useful for verification purposes, as well as to more specifically examine relationships, but clinical data was not available for analyses in the present study. Further, the efficacy and effectiveness of these assessments would need to be analyzed before assuming they are superior to self-report methods.

This lack of access to clinical data meant that several important treatment-related variables could not be examined whatsoever. There are undoubtedly medications and treatment regimens that have direct effects on sexual functioning and sexually-related variables, but the lack of access to that information circumvented those analyses and controls. Additionally, many patients undergoing treatment experience induced menopause and may subsequently undergo hormone replacement therapy (HRT). Though self-assessments of concerns about fertility were controlled for, induced menopause and HRT specifically could not be teased apart from primary hypothesized paths because such clinical data was not available for analysis. This limitation again points to the

importance for future research to be specifically designed for these purposes, and therefore pre-empt any such limitations.

Information regarding outcomes longer than 1 year post-transplant is also not available in this study. As a result, one cannot assume the longitudinal nature of any proposed relationships, particularly considering the relationships between health behaviors and SQOL outcomes changed so markedly from pre- to post-transplant. Though extant literature suggests these relationships would maintain themselves or strengthen pending significant change, longer-term assessments paired with the present analyses would still allow for greater elucidation of relationships between variables.

Related to the timeframe of this study is the limitation imposed by survivors' bias. That is, survivors are a biased group because they clearly represent a select group of HSCT patients. Specifically related to both the present and primary study, health behaviors such as tobacco use are particularly related to whether or not a patient is able to live to 1 year post-transplant; tobacco users are at an increased risk for dying within the year after receiving the transplant. Thus, not only would longer periods of time allow for better assessment, so would assessments of these variables more immediately following transplant.

Conclusion

HSCT patients face a mass amount of challenges not only with respect to treatment, but when it comes to reaching stages of survivorship without significant complications. One major complication many patients face is a strikingly worsened SQOL which, gone untreated, is most likely to worsen over time and remain significantly

pervasive for the duration of its presence. An important direction for research on outcomes in HSCT patients is to untangle the complicated web of factors that contribute to these outcomes. An important direction for providers of HSCT patients is to contribute to optimal patient outcomes, of which one is a patient's SQOL.

The present study contributes to knowledge about these outcomes by understanding the role that health behaviors may play in determining SQOL, appropriately considering sociodemographic factors, mental health variables, and treatment-related variables as best as possible. All of these variables clearly interact to, in many ways, affect the quality of a person's sex life after receiving the transplant, and subsequently the quality of their life overall. On the whole, the healthier a person's behaviors are, the greater a person's psychological well-being, and the lesser the severity of the treatment's effects, the better their SQOL, and therefore overall QOL, will be.

Researchers have a wealth of potential data to work with resultant of a population increasingly characterized by survivorship with few studies to understand how to improve such outcomes both specifically and overall. Providers have a remarkable opportunity to relatively easily impart lasting positive effects on their patients in very personally-important ways. Treating sexual health, functioning, and well-being as an equitable component of a patient's life means researching these variables intentionally and specifically. This requires presenting assessments of sexual well-being to patients as equally important as other assessments, addressing patients' problems and concerns with the same fervor as other concerns, and proactively providing information and resources to patients, particularly to those at risk for poor outcomes. Providers and patients are

empowered to make positive changes when strong, well-informed research is conducted to inform a knowledge base, and not treating sexually-related variables as equitable components of patient outcomes in this way necessarily circumvents the collection of clinical data necessary to well-informed research. HSCT patients are clearly at risk for poor SQOL outcomes, but are not receiving the guidance and support they need, and the associated paucity of research on these issues only contributes to the discrepancy between what providers and patients feel needs to be of concern with regard to their sex lives, and what is actually done when such concerns present. As has occurred throughout history, providers and researchers must take their responsibilities as trusted, expert professionals seriously and not give into socially normative topical anxiety, as it proves to be at the very least not helpful, and potentially clinically harmful.

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Table 1.

Demographic and Diagnostic Characteristics

Variable	Category	Respondents			Total Reporting		Missing	
		n	%	Valid %	n	%	n	%
Gender	Male	264	56.29	57.27	461	98.29	8	1.71
	Female	197	42.00	42.73				
Age	< 40	42	8.96	9.11	461	98.29	8	1.71
	40 - 65	324	69.08	7.28				
	> 65	95	2.26	2.61				
Race	Asian/Pacific Islander	3	.64	.68	442	94.24	27	5.76
	Black	7	1.49	1.58				
	Caucasian	427	91.04	96.61				
	Native American	4	.85	.90				
	Other (Mixed Race)	1	.21	.23				
Relationship Status	Single	46	9.81	1.07	457	97.44	12	2.56
	Divorced or separated	27	5.76	5.91				
	Married or life partner	377	8.38	82.49				
	Widowed	7	1.49	1.53				
Education Level	8^{th} grade or less	3	.64	.68	443	94.46	26	5.54
	Some high school	8	1.71	1.81				
	High School Diploma	102	21.75	23.02				
	Some college	141	3.06	31.83				
	4 year college degree	89	18.98	2.09				
	Post-graduate studies	100	21.32	22.57				
Employment Status	Employed	195	41.58	43.33	450	95.95	19	4.05
	Unemployed	30	6.40	6.67				
	Work disabled	36	7.68	8.00				
	Student	7	1.49	1.56				
	Retired	115	24.52	25.56				
	Self-employed	42	8.96	9.33				
	Full-time homemaker	16	3.41	3.56				
	Other	9	1.92	2.00				
Transplant Type	Allogeneic	87	18.59	18.66	461	98.29	8	1.71
	Autologous	374	79.74	81.13				
Diagnosis	Amyloidosis	51	1.87	11.09	460	98.08	9	1.92
	Benign Disorders	2	.43	.43				
	Leukemias	61	13.01	13.26				
	Lymphomas	124	26.44	26.96				
	Myelodysplastic or Myeloproliferative Disorders	23	4.90	5.00				
	Other Malignancies	2	.43	.43				
	Plasma Cell (ex. amyloid)	197	42.00	42.83				

Table 2.

Pre-transplant health behavior response rates

Prompt	**Most recent tobacco use**				
Response options	0-7 days	8 days – 6 months	6-12 months	12+ months	Never
% responded	6.30%	6.30%	1.40%	38.10%	48.10%
Response options	Current		Former		Never
% responded	13.70%		38.10%		48.10%
Prompt	**Aerobic exercise**				
Response options	None	< 30 min.	30-59 min.	1-3 hours	3+ hours
% responded	15.10%	17.30%	24.30%	34.70%	8.40%
Response options	Meeting guidelines		Not meeting guidelines		
% responded	21.50%		78.50%		
Prompt	**Fruit & vegetable consumption**				
Response options	0	1	2	3-4	5-6	7+
% responded	1.20%	2.60%	17.20%	47.20%	16.50%	14.40%
Response options	Meeting guidelines		Not meeting guidelines		
% responded	3.90%		69.10%		
Prompt	**Typical alcohol use in past year**				
Response options	Never	< Monthly	2-4/month	2-3/week	4+/week
% responded	3.80%	25.20%	19.60%	13.60%	1.70%
Prompt	**Typical drinking day**				
Response options	1-2	3-4	5-6	7-9	10+
% responded	87.50%	11.40%	1.10%	.00%	.00%
Prompt	**Binge drinking episodes**				
Response options	Never	< Monthly	Monthly	Weekly	Daily+
% responded	78.50%	17.80%	2.70%	1.00%	.00%
Prompt	**Received recommendation to exercise more**				
Response options	Yes		No		
% responded	3.48%		69.52%		
Prompt	**Received recommendation to eat better**				
Response options	Yes		No		
% responded	25.87%		74.13%		

Prompt	**Received recommendation to lose weight**			
Response options	Yes	No		
% responded	21.71%	78.29%		
Prompt	**Received recommendation to reduce alcohol use**			
Response options	Yes	No		
% responded	3.94%	96.06%		
Prompt	**Received recommendation to quit tobacco**			
Response options	Yes	No		
% responded	8.10%	91.90%		
Prompt	**Change in exercise since transplant-related diagnosis**			
Response options	Increased	Stayed the same	Decreased	
% responded	11.30%	44.20%	44.40%	
Prompt	**Change in healthy eating since transplant-related diagnosis**			
Response options	Increased	Stayed the same	Decreased	
% responded	4.00%	49.30%	1.70%	
Prompt	**Change in weight since transplant-related diagnosis**			
Response options	Increased	Stayed the same	Decreased	
% responded	2.50%	38.80%	4.70%	
Prompt	**Change in alcohol use since transplant-related diagnosis**			
Response options	Increased	Stayed the same	Decreased	N/A
% responded	.20%	19.00%	28.60%	52.10%
Prompt	**Change in tobacco use since transplant-related diagnosis**			
Response options	Increased	Stayed the same	Decreased	N/A
% responded	.70%	3.60%	6.20%	89.60%

Table 3.

Post-Transplant Health Behavior Response Rates

Prompt	**Most recent tobacco use**				
Response options	0-7 days	8 days – 6 months	6-12 months	12+ months	Never
% responded	5.00%	2.00%	2.00%	40.10%	50.80%
Response options	Current		Former		Never
% responded	8.90%		4.20%		5.90%
Prompt	**Aerobic exercise**				
Response options	None	< 30 min.	30-59 min.	1-3 hours	3+ hours
% responded	11.80%	15.10%	17.00%	43.10%	12.90%
Response options	Meeting guidelines			Not meeting guidelines	
% responded	26.60%			69.40%	
Prompt	**Fruit & vegetable consumption**				
Response options	0	1	2	3-4	5-6	7+
% responded	1.10%	5.60%	17.40%	41.60%	19.30%	15.00%
Response options	Meeting guidelines			Not meeting guidelines	
% responded	34.30%			65.70%	
Prompt	**Typical alcohol use in past year**				
Response options	Never	< Monthly	2-4/month	2-3/week	4+/week
% responded	41.40%	19.50%	2.10%	11.70%	7.30%
Prompt	**Typical drinking day**				
Response options	1-2	3-4	5-6	7-9	10+
% responded	86.90%	11.50%	1.50%	.00%	.00%
Prompt	**Received recommendation to exercise more**				
Response options	Yes			No	
% responded	45.93%			54.07%	
Prompt	**Received recommendation to eat better**				
Response options	Yes			No	
% responded	35.45%			64.55%	
Prompt	**Received recommendation to lose weight**				
Response options	Yes			No	
% responded	13.00%			87.00%	

Prompt	**Received recommendation to gain weight**			
Response options	Yes		No	
% responded	15.87%		84.13%	
Prompt	**Received recommendation to reduce alcohol use**			
Response options	Yes	No	Not applicable	
% responded	4.82%	46.93%	48.25%	
Prompt	**Received recommendation to quit tobacco**			
Response options	Yes	No	Not applicable	
% responded	5.01%	13.07%	81.92%	
Prompt	**Change in exercise since transplant-related diagnosis**			
Response options	Increased	Stayed the same	Decreased	
% responded	38.80%	35.90%	25.30%	
Prompt	**Change in healthy eating since transplant-related diagnosis**			
Response options	Increased	Stayed the same	Decreased	
% responded	49.10%	45.40%	5.40%	
Prompt	**Change in weight since transplant-related diagnosis**			
Response options	Increased	Stayed the same	Decreased	
% responded	37.80%	3.30%	31.90%	
Prompt	**Change in alcohol use since transplant-related diagnosis**			
Response options	Increased	Stayed the same	Decreased	N/A
% responded	2.40%	24.20%	19.50%	53.90%
Prompt	**Change in tobacco use since transplant-related diagnosis**			
Response options	Increased	Stayed the same	Decreased	N/A
% responded	.90%	3.40%	3.40%	92.20%

Table 4.

Pre- and Post-Transplant Sexual Interest and Satisfaction Response Rates and Longitudinal Analyses

Pre-Transplant					
Prompt	**Recent Losses of Interest in sex** (n = 150)				
Response options	No change	Less interested		Much less	Complete loss
% responded	51.30%	29.30%		1.70%	8.70%
Prompt	**I am satisfied with my sex life** (n = 78)				
Response options	Not at all	A little bit	Somewhat	Quite a bit	Very much
% responded	14.10%	19.20%	19.20%	2.50%	26.90%
Refused to answer n = 30					
Post-Transplant					
Prompt	**I am interested in sex** (n = 451)				
Response options	Not at all	A little bit	Somewhat	Quite a bit	Very much
% responded	19.50%	18.80%	3.60%	17.50%	13.50%
Prompt	**I am satisfied with my sex life** (n = 356)				
Response options	Not at all	A little bit	Somewhat	Quite a bit	Very much
% responded	29.50%	12.10%	24.40%	18.00%	16.00%
Refused to answer n = 99					
Longitudinal SQOL outcomes					
		R^2	F	β	p
Interest		.10	15.66	-.32	< .001
Satisfaction		.14	1.50	.37	.00
Refusal to answer		.11	21.29	.34	< .001
Refusal to answer predicting interest cross-sectionally					
Pre-transplant		.01	1.20	-.09	.28
Post-transplant		.07	34.88	-.27	< .001

Table 5.

Numeric Values (Dummy-Coding) Assigned to Variables and Associated Response Options

Variable	Response Option	Assigned Numeric Value
Tobacco use	Never	1
	More than 12 months ago	2
	6 to 12 months ago	3
	8 days to 6 months ago	4
	0 to 7 days ago	5
	Never	1
	Former	2
	Current	3
Meeting CDC guidelines for alcohol consumption	Does not drink	0
	Does not meet guidelines	1
	Meets guidelines	2
Exercise	None	0
	Less than 30 minutes	15
	30 to 59 minutes	45
	1 to 3 hours	120
	More than 3 hours	180
Meeting CDC guidelines for aerobic exercise	Does not meet guidelines	0
	Meets guidelines	1
Fruit & vegetable consumption	0	0
	1	1
	2	2
	3 to 4	3.5
	5 to 6	5.25
	7 or more	7
Meeting CDC guidelines for fruit & vegetable consumption	Does not meet guidelines	0
	Meets guidelines	1
Healthcare provider recommendations for behavior change	I do not drink/use tobacco	0
	Yes (received advice)	1
	No (did not receive advice)	2

Changes in behavior since diagnosis	Decreased	100
	Stayed the same	200
	Increased	300
Adherence to healthcare provider recommendations	Did not follow advice	0
	Followed advice	1
Gender	Female	0
	Male	1
Transplant type	Allogeneic	0
	Autologous	1
Relationship status	Not partnered	0
	Partnered	1
Education Level	8th grade or less	1
	Some high school	2
	High School Diploma	3
	Some college	4
	4 year college degree	5
	Post-graduate studies	6

Note. All coding systems were identical for pre-transplant and post-transplant survey items. Items not addressed in this table utilized pre-assigned scales and coding. See Appendices H and I for these values; assigned numeric values are located next to response options.

Table 6.

Coding for Variables Utilized in Analyses Tables

Variable		Measurement scale	Coding
Most recent tobacco use		Continuous	TC
		Current (within last year) vs. Former (more than a year ago) vs. Never	TT
Regular aerobic exercise		Continuous	XC
		Dichotomized according to CDC Guidelines (150 minutes per week)	XD
Alcohol use		Last year alcohol use regularity	AY
		Typical drinking day alcohol consumption	AT
		AUDIT Total*	AU
		Binge drinking episode regularity*	AB
		Dichotomized according to CDC guidelines	AD
Fruit & vegetable consumption		Continuous	EC
		Dichotomized according to CDC Guidelines (5 total servings per day)	ED
Healthcare provider recommendations for change	Increase aerobic exercise	Yes/No	HX
	Eat more healthy foods		HE
	Lose weight		HL
	Gain weight**		HG
	Reduce alcohol use		HA
	Quit tobacco		HT
Behavior change	Regular aerobic exercise	Increased/Stayed the same/Decreased	CX
	Healthy food consumption		CE
	Weight		CW
	Alcohol use		CA
	Tobacco use		CT
Adherence to healthcare providers' recommendations	Increase aerobic exercise	Adhered/Did not adhere	FX
	Eat more healthy foods		FE
	Lose weight		FL
	Gain weight**		FG
	Reduce alcohol use		FA
	Quit tobacco		FT

Note. * = only assessed pre-transplant; ** = only assessed post-transplant

Table 7.

Relationships Between Health Behaviors from Pre- to Post-Transplant

Health Behavior	*n*	*SEE*	R^2	*F*	*b*	*SE*	β	*p*
TC	423	.58	.62	694.29	.67	.03	.79	< .001
TT	422	.38	.65	776.37	.74	.03	.81	< .001
XC	406	89.20	.16	75.53	.45	.05	.40	< .001
XD	406	.43	.10	43.95	.34	.05	.31	< .001
AY	412	.88	.53	467.64	.69	.03	.73	< .001
AT	210	.38	.10	21.99	.36	.08	.31	< .001
AU	*Not assessed post-transplant*							
AB	*Not assessed post-transplant*							
AD	392	.52	.31	172.80	.57	.04	.55	< .001
EC	423	1.71	.30	183.38	.59	.04	.55	< .001
ED	423	.41	.27	151.97	.53	.04	.52	< .001
HX	419	.48	.07	32.86	.29	.05	.27	< .001
HE	421	.47	.04	19.21	.23	.05	.21	< .001
HL	419	.32	.14	67.04	.31	.04	.37	< .001
HA	418	.58	.01	5.77	.37	.15	.12	.017
HT	423	.46	.23	122.47	.91	.08	.47	< .001
CX	413	78.84	.02	6.69	.15	.06	.13	.010
CE	413	58.36	.04	15.92	.18	.04	.19	< .001
CW	399	83.61	.00	1.39	.07	.06	.06	.240
CA	414	58.78	.25	136.42	.59	.05	.50	< .001
CT	417	33.68	.13	63.56	.38	.05	.36	< .001
FX	77	.49	.01	.52	.10	.14	.08	.474
FE	52	.49	.06	2.95	.23	.14	.23	.092
FL	30	.49	.04	1.08	.18	.18	.19	.307
FA	*Insufficient number of respondents*							
FT	12	.48	.19	2.54	.50	.31	.43	.139

Note. SEE = standard error of the estimate; *SE* = standard error of the regression coefficient

Table 8.

Prospective Predictions of Satisfaction with One's Sex Life

Health Behavior	*n*	*SEE*	R^2	*F*	*b*	*SE*	β	*p*
TC	324	1.44	.00	.53	- .05	.70	- .04	.469
TT	324	1.44	.00	.29	- .06	.11	- .03	.588
XC	319	1.45	.00	.02	.00	.00	- .01	.878
XD	319	1.44	.00	.65	- .16	.19	- .05	.422
AY	322	1.43	.00	.00	- .00	.06	.00	.955
AT	225	1.42	.01	2.61	- .43	.26	- .11	.107
AU	223	1.43	.00	.50	.05	.05	- .05	.482
AB	240	1.44	.00	.13	.06	.16	.02	.717
AD	308	1.43	.00	.11	- .05	.14	- .02	.739
EC	325	1.44	.00	1.23	.05	.04	.06	.268
ED	325	1.44	.00	.80	.16	.17	.05	.371
HX	327	1.44	.00	.04	.03	.17	.01	.845
HE	327	1.44	.00	.35	.11	.18	.03	.553
HL	327	1.44	.00	1.32	- .22	.19	- .06	.252
HA	326	1.44	.00	.12	.13	.39	.02	.735
HT	327	1.44	.01	3.50	.53	.28	.10	.062
CX	321	1.44	.02	4.72	.00	.00	.12	.031
CE	321	1.45	.00	.29	.00	.00	.03	.589
CW	315	1.44	.00	.03	.00	.00	.01	.866
CA	318	1.44	.00	.00	.00	.00	.00	.994
CT	320	1.44	.01	3.47	- .00	.00	- .10	.063
FX	97	1.42	.00	.00	.01	.39	.00	.988
FE	84	1.42	.00	.01	- .04	.31	- .01	.908
FL	73	1.40	.00	.02	- .04	.33	- .02	.898
FA	13	1.48	.04	.45	- .56	.83	- .19	.513
FT	24	1.35	.00	.06	- .13	.54	- .05	.813

Note. SEE = standard error of the estimate; *SE* = standard error of the regression coefficient

Table 9.

Prospective Predictions of Interest in Sex

Health Behavior	*n*	*SEE*	R^2	*F*	*b*	*SE*	β	*p*
TC	413	1.27	.01	3.42	.10	1.27	.09	.065
TT	413	1.27	.01	5.07	.20	.09	.11	.025
XC	406	1.27	.01	5.40	.00	.00	.12	.021
XD	406	1.28	.00	.00	.00	.15	.00	.984
AY	411	1.26	.03	14.03	.17	.05	.18	< .001
AT	266	1.24	.00	.13	.07	.20	.02	.718
AU	264	1.24	.00	.47	.03	.04	.04	.492
AB	282	1.24	.01	1.45	.16	.13	.07	.229
AD	396	1.25	.04	18.18	.45	.11	.21	< .001
EC	414	1.27	.01	2.67	.06	.03	.08	.103
ED	414	1.27	.01	5.37	.31	.14	.11	.021
HX	416	1.28	.01	2.27	.20	.14	.07	.133
HE	416	1.28	.00	1.49	.17	.14	.06	.222
HL	416	1.28	.00	1.44	- .18	.15	- .06	.230
HA	414	1.28	.01	2.30	- .50	.33	- .07	.130
HT	416	1.28	.00	.01	- .02	.23	- .00	.930
CX	406	1.28	.00	.25	.00	.00	- .03	.620
CE	405	1.28	.00	1.49	.00	.00	.06	.223
CW	399	1.27	.02	7.46	.00	.00	.14	.007
CA	403	1.26	.03	11.54	.00	.00	.17	.001
CT	405	1.28	.00	.58	.00	.00	.04	.446
FX	120	1.11	.00	.28	.15	.28	.05	.599
FE	104	1.15	.01	.58	.17	.23	.08	.450
FL	86	1.22	.00	.07	- .07	.26	- .03	.787
FA	15	1.12	.00	.01	.05	.56	.02	.934
FT	28	1.23	.13	3.84	- .91	.47	- .35	.060

Note. SEE = standard error of the estimate; *SE* = standard error of the regression coefficient

Table 10.

Cross-Sectional Analyses of Satisfaction with One's Sex Life

Health Behavior	*n*	*SEE*	R^2	*F*	*b*	*SE*	β	*p*
TC	350	1.44	.00	1.34	- .09	.08	- .06	.247
TT	350	1.44	.00	.56	- .09	.12	- .04	.456
XC	344	1.44	.01	1.78	.00	.00	.07	.183
XD	344	1.44	.00	.09	.05	.17	.02	.764
EC	350	1.43	.10	3.49	.07	.04	.10	.063
ED	350	1.44	.00	1.30	.19	.16	.06	.255
AY	345	1.44	.01	2.85	.10	.06	.09	.092
AT	213	1.41	.01	1.74	.31	.24	.09	.188
AD	341	1.44	.00	.87	.12	.13	.05	.353
HX	346	1.43	.01	4.12	.31	.16	.11	.043
HE	347	1.43	.01	4.36	.33	.16	.11	.038
HL	345	1.44	.00	1.14	.24	.22	.06	.286
HG	335	1.45	.00	.26	.04	.07	.03	.611
HA	346	1.44	.00	.01	- .07	.08	.01	.914
HT	349	1.44	.00	1.35	- .10	.11	.06	.247
CX	348	1.44	.01	3.47	.04	.04	.10	.063
CE	350	1.44	.00	.04	- .02	.04	.01	.846
CW	343	1.44	.00	.46	- .01	.04	- .04	.497
CA	351	1.44	.00	.21	.03	.08	.03	.646
CT	353	1.44	.00	1.40	- .19	.16	- .06	.238
FX	152	1.42	.02	2.70	.38	.23	.13	.102
FE	119	1.49	.00	.08	- .08	.28	- .03	.780
FL	48	1.33	.00	.02	.18	.44	.06	.881
FG	44	1.66	.00	.16	- .07	.49	- .02	.690
FA	18	1.48	.03	.61	- .60	.77	- .19	.447
FT	15	1.75	.02	.35	.53	.90	.16	.565

Note. SEE = standard error of the estimate; *SE* = standard error of the regression coefficient

Table 11.

Cross-Sectional Analyses of Interest in Sex

Health Behavior	*n*	*SEE*	R^2	*F*	*b*	*SE*	β	*p*
TC	444	1.29	.00	1.85	.08	.06	.06	.175
TT	444	1.29	.01	3.39	.17	.09	.09	.066
XC	435	1.27	.04	17.06	.00	.00	.19	< .001
XD	435	1.28	.02	8.98	.42	.14	.14	.003
EC	445	1.30	.00	.31	.02	.03	.03	.575
ED	445	1.29	.00	2.67	.21	.13	.08	.101
AY	436	1.26	.05	23.81	.23	.05	.23	< .001
AT	247	1.22	.01	1.88	.27	.20	.09	.172
AD	431	1.26	.05	23.09	.47	.10	.23	< .001
HX	437	1.28	.02	6.99	.23	.09	.13	.009
HE	439	1.29	.01	3.52	.23	.13	.09	.061
HL	436	1.30	.00	.01	.01	.18	.00	.928
HG	423	1.30	.00	.01	.01	.06	.01	.918
HA	439	1.28	.02	9.91	.21	.06	- .15	.002
HT	442	1.30	.00	1.23	- .05	.09	.05	.267
CX	441	1.29	.02	1.29	.06	.04	.15	.001
CE	442	1.29	.02	7.87	.05	.04	.13	.005
CW	434	1.30	.00	1.27	- .00	.04	.05	.260
CA	444	1.26	.06	28.56	.35	.07	.25	< .001
CT	446	1.30	.00	.06	.02	.13	.01	.814
FX	200	1.19	.04	8.69	.50	.17	.21	.004
FE	156	1.26	.01	2.21	.31	.21	.12	.139
FL	64	1.23	.01	.89	.39	.38	.12	.349
FG	54	1.29	.02	1.02	.31	.33	.14	.316
FA	21	1.11	.01	.13	- .20	.57	- .08	.728
FT	21	1.29	.00	.05	.13	.57	.05	.829

Note. SEE = standard error of the estimate; *SE* = standard error of the regression coefficient

Table 12.

Gender Moderating Health Behaviors Affecting Post-Transplant Sexual Interest

Factors	*F*	*df*	*dfr*	*p*
Gender X TT	.07	2	430	.937
Gender X XD	1.42	1	424	.233
Gender X AD	.88	2	418	.416
Gender X HX	.99	1	426	.322
Gender X HE	.08	1	428	.783
Gender X HL	.07	1	426	.791
Gender X HG	.12	1	412	.727
Gender X HA	2.26	2	426	.105
Gender X HT	.07	2	429	.933
Gender X CX	.99	2	428	.373
Gender X CE	2.22	2	429	.109
Gender X CW	.59	2	421	.556
Gender X CA	1.92	3	430	.125
Gender X CT	1.12	3	431	.339
Gender X FX	.39	1	194	.533
Gender X FE	6.89	1	150	.010
Gender X FL	.30	1	61	.584
Gender X FG	1.91	1	51	.173
Gender X FA	.65	1	18	.432
Gender X FT	*Insufficient number of respondents*			
Gender X ED	.55	1	434	.458

Note. *df* = degrees of freedom; *dfr* = residual degrees of freedom

Table 13.
Gender Moderating Health Behaviors Affecting Post-Transplant Sexual Satisfaction

Factors	*F*	*df*	*dfr*	*p*
Gender X TT	.77	2	336	.463
Gender X XD	.61	1	333	.434
Gender X AD	3.11	2	328	.046
Gender X HX	.07	1	335	.795
Gender X HE	.29	1	336	.588
Gender X HL	.28	1	335	.599
Gender X HG	1.36	1	324	.244
Gender X HA	.83	2	333	.436
Gender X HT	.12	2	336	.887
Gender X CX	.23	2	335	.797
Gender X CE	3.20	2	337	.042
Gender X CW	.08	2	330	.083
Gender X CA	1.07	3	337	.362
Gender X CT	.96	3	338	.410
Gender X FX	.01	1	146	.909
Gender X FE	1.24	1	113	.267
Gender X FL	.19	1	45	.668
Gender X FG	.03	1	41	.873
Gender X FA	.68	1	15	.422
Gender X FT	*Insufficient number of respondents*			
Gender X ED	.04	1	339	.848

Note. *df* = degrees of freedom; *dfr* = residual degrees of freedom

Table 14.

Gender and Partnership Status Moderating Predictions of Post-Transplant Sexual Satisfaction

Predictor		Gender		*t*	Partnership Status		*t*
		Male	Female		Partnered	Not Partnered	
TC	*n*	261	192	- .15	371	78	1.03
	b	- .055	- .034		- .067	- .207	
	SEE	1.431	1.4		1.435	1.473	
	s	1.109	.716		.938	1.17	
XC	*n*	255	188	1.64	363	76	.55
	b	.002	0		.001	0	
	SEE	1.417	1.404		1.435	1.476	
	s	101.81148	89.35928		10.14216	82.0745	
CX	*n*	259	192	.70	368	79	.00
	b	.002	.001		.002	.002	
	SEE	1.423	1.404		1.43	1.466	
	s	8.041	78.371		79.863	77.111	
CE	*n*	260	192	3.70***	369	79	1.90
	b	.003	- .004		.001	- .004	
	SEE	1.42	1.371		1.432	1.462	
	s	59.679	59.28		6.143	56.657	
CW	*n*	256	188	2.20*	362	78	1.06
	b	.001	- .002		0	- .002	
	SEE	1.43	1.376		1.433	1.468	
	s	82.537	84.319		83.991	79.542	
CA	*n*	261	194	2.44*	372	79	.00
	b	.002	- .002		.001	.001	
	SEE	1.422	1.398		1.436	1.473	
	s	69.681	68.002		66.632	79.346	
CT	*n*	262	194	-1.52	373	79	1.49
	b	- .003	.002		- .001	- .006	
	SEE	1.424	1.402		1.437	1.453	
	s	39.857	31.363		33.636	48.801	
AY	*n*	260	184	2.85**	362	78	-1.16
	b	.194	- .061		.088	.239	
	SEE	1.404	1.392		1.426	1.462	
	s	1.346	1.229		1.34	1.139	
AT	*n*	157	98	2.41*	205	48	.57
	b	.622	- .306		.504	.278	
	SEE	1.379	1.423		1.394	1.513	
	s	.4	.398		.332	.589	
EC	*n*	259	194	- .69	372	77	2.95**
	b	.03	.068		.09	- .125	
	SEE	1.421	1.394		1.421	1.458	
	s	1.96291	2.13312		2.05729	2.09072	

Note. SEE = standard error of the estimate, * < .05, ** < .01, *** < .001

Table 15.

Gender and Partnership Status Moderating Predictions of Post-Transplant Sexual Interest

Predictor		Gender		*t*	Partnered Status		*t*
		Male	Female		Partnered	Not Partnered	
TC	*n*	261	192	- .90	371	78	- .15
	b	- .003	.11		.091	.11	
	SEE	1.293	1.145		1.267	1.384	
	s	1.109	.716		.938	1.17	
XC	*n*	255	188	- .90	363	76	.56
	b	.002	.003		.003	.002	
	SEE	1.287	1.121		1.238	1.411	
	s	101.81148	89.35928		10.14216	82.0745	
CX	*n*	259	192	.76	368	79	- .53
	b	.003	.002		.002	.003	
	SEE	1.282	1.137		1.258	1.394	
	s	8.041	78.371		79.863	77.111	
CE	*n*	260	192	-2.28*	369	79	- .39
	b	.001	.005		.003	.004	
	SEE	1.297	1.125		1.261	1.398	
	s	59.679	59.28		6.143	56.657	
CW	*n*	256	188	1.01	362	78	.00
	b	.001	0		.001	.001	
	SEE	.183	1.167		1.274	1.424	
	s	82.537	84.319		83.991	79.542	
CA	*n*	261	194	- .67	372	79	- .53
	b	.004	.005		.004	.005	
	SEE	1.269	1.117		1.24	1.355	
	s	69.681	68.002		66.632	79.346	
CT	*n*	262	194	.33	373	79	2.46*
	b	-4.93E-06	- .001		.003	- .005	
	SEE	1.301	1.16		1.27	1.397	
	s	39.857	31.363		33.636	48.801	
AY	*n*	260	184	-1.44	362	78	- .90
	b	.156	.275		.211	.323	
	SEE	1.276	1.124		1.24	1.356	
	s	1.346	1.229		1.34	1.139	
AT	*n*	157	98	.34	205	48	.29
	b	.341	.224		.319	.211	
	SEE	1.235	1.111		1.194	1.348	
	s	.4	.398		.332	.589	
EC	*n*	259	194	- .12	372	77	.65
	b	.034	.04		.022	- .024	
	SEE	1.305	1.156		1.272	1.413	
	s	1.96291	2.13312		2.05729	2.09072	

Note. SEE = standard error of the estimate, * < .05, ** < .01, *** < .001

Table 16.

Partnership Status Moderating Health Behaviors Predicting Sexual Interest

Factors	*F*	*df*	*dfr*	*p*
Partnership status X TT	1.85	2	426	.159
Partnership status X XD	1.88	1	420	.171
Partnership status X AD	.28	2	414	.757
Partnership status X HX	.78	1	422	.379
Partnership status X HE	.81	1	424	.368
Partnership status X HL	.41	1	422	.523
Partnership status X HG	4.14	1	408	.042
Partnership status X HA	2.88	2	422	.057
Partnership status X HT	.62	2	425	.538
Partnership status X CX	.22	2	424	.804
Partnership status X CE	.91	2	425	.405
Partnership status X CW	.16	2	417	.855
Partnership status X CA	1.68	3	426	.172
Partnership status X CT	1.70	3	427	.167
Partnership status X FX	.26	1	193	.612
Partnership status X FE	.07	1	148	.794
Partnership status X FL	.05	1	60	.833
Partnership status X FG	2.24	1	51	.141
Partnership status X FA	.00	1	18	.989
Partnership status X FT	.11	1	18	.741
Partnership status X ED	.00	1	430	.955

Note. *df* = degrees of freedom; *dfr* = residual degrees of freedom

Table 17.

Partnership Status Moderating Health Behaviors Predicting Sexual Satisfaction

Factors	*F*	*df*	*dfr*	*p*
Partnership status X TT	1.05	2	332	.350
Partnership status X XD	.22	1	329	.636
Partnership status X AD	.01	2	324	.995
Partnership status X HX	.87	1	331	.351
Partnership status X HE	2.78	1	332	.096
Partnership status X HL	2.31	1	331	.129
Partnership status X HG	.04	1	320	.834
Partnership status X HA	.12	2	329	.891
Partnership status X HT	2.57	2	332	.078
Partnership status X CX	.20	2	331	.816
Partnership status X CE	.89	2	333	.412
Partnership status X CW	.26	2	326	.768
Partnership status X CA	.42	3	333	.740
Partnership status X CT	1.41	3	334	.240
Partnership status X FX	1.13	1	145	.289
Partnership status X FE	3.84	1	111	.053
Partnership status X FL	3.12	1	44	.084
Partnership status X FG	.10	1	41	.752
Partnership status X FA	.46	1	15	.507
Partnership status X FT	.86	1	12	.373
Partnership status X ED	1.60	1	335	.207

Note. *df* = degrees of freedom; *dfr* = residual degrees of freedom

Table 18.

Education Moderating Health Behaviors Predicting Sexual Interest

Centered Model								
Moderator	Predictor	β	R^2	*F*	*df*	*dfr*	ΔR^2	*p*
Education	TC	.05	.00	.49	1	417	- .003	.484
Education	TT	--	--	.88	9	401	--	.544
Education	XC	- .01	.00	.00	1	408	- .038	.959
Education	XD	--	--	1.73	4	399	--	.142
Education	HX	--	--	1.67	4	402	--	.156
Education	HE	--	--	.32	4	404	--	.864
Education	HL	--	--	.19	3	402	--	.904
Education	HG	--	--	1.14	5	387	--	.339
Education	HA	--	--	.45	7	400	--	.872
Education	HT	--	--	.85	8	402	--	.561
Education	CX	--	--	1.60	10	399	--	.105
Education	CE	--	--	1.89	9	401	--	.053
Education	CW	--	--	1.30	8	393	--	.243
Education	CA	--	--	1.60	10	401	--	.105
Education	CT	--	--	1.10	10	402	--	.363
Education	FT	--	--	1.77	5	181	--	.121
Education	FE	--	--	2.63	5	139	--	.026
Education	FL	--	--	.60	3	52	--	.619
Education	FG	--	--	.68	3	44	--	.571
Education	FA	--	--	.68	2	15	--	.520
Education	FT	--	--	.29	3	10	--	.831
Education	AY	- .05	.00	.96	1	411	- .050	.327
Education	AT	- .03	.00	.19	1	231	- .007	.663
Education	AD	--	--	.32	7	393	--	.945
Education	EC	.07	.01	2.26	1	418	+ .004	.134
Education	ED	--	--	1.10	5	408	--	.864

Note. *df* = degrees of freedom; *dfr* = residual degrees of freedom

Table 19.

Education Moderating Health Behaviors Predicting Sexual Satisfaction

Centered Model								
Moderator	Predictor	β	R^2	*F*	*df*	*dfr*	ΔR^2	*p*
Education	TC	.07	.00	XXXX	1	326	.000	.231
Education	TT	--	--	.76	9	310	--	.835
Education	XC	.01	.00	.04	1	320	- .005	.912
Education	XD	--	--	.62	4	311	--	.647
Education	HX	--	--	1.82	4	314	--	.125
Education	HE	--	--	2.46	4	315	--	.046
Education	HL	--	--	.39	4	313	--	.814
Education	HG	--	--	.59	5	302	--	.708
Education	HA	--	--	.78	7	310	--	.605
Education	HT	--	--	1.59	8	312	--	.126
Education	CX	--	--	.88	9	310	--	.540
Education	CE	--	--	1.36	9	312	--	.204
Education	CW	--	--	.84	8	305	--	.571
Education	CA	--	--	.81	10	311	--	.616
Education	CT	--	--	1.67	9	313	--	.095
Education	FT	--	--	.55	5	134	--	.742
Education	FE	--	--	1.11	5	102	--	.362
Education	FL	--	--	1.63	3	36	--	.199
Education	FG	--	--	1.79	3	33	--	.169
Education	FA	--	--	1.43	2	12	--	.277
Education	FT	--	--	8.93	5	14	--	.019
Education	AY	- .01	.00	.05	1	323	- .008	.817
Education	AT	.00	.00	.00	1	199	- .008	.950
Education	AD	--	--	.96	7	306	--	.464
Education	EC	- .01	.00	.04	1	326	- .099	.836
Education	ED	--	--	.06	3	318	--	.046

Note. *df* = degrees of freedom; *dfr* = residual degrees of freedom

Table 20.

Age Moderating Health Behaviors Predicting Sexual Interest

Centered Model								
Moderator	Predictor	β	R^2	*F*	*df*	*dfr*	ΔR^2	*p*
Age	TC	- .04	.04	5.71	3	433	+ .04	.462
Age	TT	- .05	.05	6.72	3	432	+ .04	.303
Age	XC	- .01	.07	11.18	3	424	+ .03	.878
Age	XD	- .01	.06	8.60	3	424	+ .04	.900
Age	HX	- .03	.06	8.68	3	426	+ .04	.524
Age	HE	- .07	.06	8.35	3	428	+ .05	.126
Age	HL	.00	.04	5.35	3	426	+ .04	.959
Age	HG	.02	.03	4.89	3	413	+ .03	.725
Age	HA	- .03	.05	7.96	3	428	+ .04	.555
Age	HT	- .01	.04	6.14	3	431	+ .04	.829
Age	CX	- .04	.06	9.47	3	430	+ .04	.407
Age	CE	.08	.06	8.82	3	431	+ .04	.099
Age	CW	.01	.04	5.60	3	423	+ .04	.877
Age	CA	.08	.09	14.68	3	434	+ .03	.106
Age	CT	.07	.04	6.36	3	435	+ .04	.120
Age	FX	- .09	.08	5.25	3	194	+ .04	.216
Age	FE	.12	.04	2.16	3	150	+ .03	.129
Age	FL	- .08	.07	1.60	3	61	+ .06	.550
Age	FG	- .04	.04	.65	3	51	+ .02	.803
Age	FA	.09	.19	1.37	3	18	+ .18	.814
Age	FT	.10	.04	.24	3	18	+ .04	.730
Age	AY	.02	.09	14.08	3	425	+ .04	.673
Age	AT	.03	.03	2.40	3	239	+ .02	.722
Age	AD	.37	.09	13.71	3	420	+ .04	.079
Age	EC	.00	.04	5.48	3	434	+ .04	.959
Age	ED	.00	.04	6.12	3	434	+ .04	.942

Note. *df* = degrees of freedom; *dfr* = residual degrees of freedom

Table 21.

Age Moderating Health Behaviors Predicting Sexual Satisfaction

Centered Model								
Moderator	Predictor	β	R^2	*F*	*df*	*dfr*	ΔR^2	*p*
Age	TC	- .04	.01	.65	3	339	+ .01	.509
Age	TT	.02	.00	.25	3	338	.00	.783
Age	XC	.05	.01	.83	3	333	.00	.386
Age	XD	.05	.00	.26	3	333	.00	.414
Age	HX	.03	.01	1.46	3	335	.00	.582
Age	HE	.04	.02	2.00	3	336	+ .01	.449
Age	HL	.07	.01	.94	3	335	+ .01	.207
Age	HG	- .08	01	.55	3	325	.00	.278
Age	HA	- .02	.00	.13	3	335	.00	.781
Age	HT	- .08	.01	1.18	3	338	+ .01	.162
Age	CX	- .04	.01	1.20	3	337	.00	.421
Age	CE	.10	.01	1.09	3	339	+ .01	.081
Age	CW	- .08	.01	.85	3	332	+ .01	.135
Age	CA	- .09	.01	.85	3	341	+ .01	.143
Age	CT	.00	.00	.48	3	342	.00	.956
Age	FX	- .16	.05	2.38	3	146	+ .03	.047
Age	FE	.11	.01	.53	3	113	+ .01	.251
Age	FL	- .26	.10	1.45	3	41	+ .10	.098
Age	FG	- .46	.21	4.05	3	45	+ .21	.002
Age	FA	- .09	.06	.32	3	15	+ .03	.824
Age	FT	.37	.13	.57	3	12	+ .11	.364
Age	AY	- .06	.01	1.32	3	334	.00	.289
Age	AT	- .04	.01	.73	3	205	.00	.674
Age	AD	- .41	.01	1.19	3	330	+ .01	.103
Age	EC	.06	.01	1.38	3	339	- .09	.260
Age	ED	.06	.01	.78	3	339	+ .01	.242

Note. *df* = degrees of freedom; *dfr* = residual degrees of freedom

Table 22.

Depression as a Mediator of Health Behaviors Predicting Sexual Interest

Variables	Individual Models						Mediation Models						ΔR^2
	R^2	β	*F*	*df*	*dfr*	*p*	R^2	β	*F*	*df*	*dfr*	*p*	
TT	.01	.09	3.39	1	442	.07	.08	- .28	6.57	2	148	.001	+ .07
Depression	.07	- .27	11.93	1	152	< .001		.10				.206	
XC	.04	.19	17.06	1	434	< .001	.07	- .25	5.33	2	148	.002	+ .03
Depression	.07	- .27	11.93	1	152	< .001		.03				.684	
XD	.02	.14	8.98	1	434	.003	.07	- .27	5.62	2	148	.001	+ .05
Depression	.07	- .27	11.93	1	152	< .001		.07				.400	
HX	.02	.13	6.99	1	436	.009	.09	- .29	7.20	2	146	< .001	+ .07
Depression	.07	- .27	11.93	1	152	< .001		.07				.393	
HE	.01	.09	3.52	1	438	.06	.09	- .30	7.50	2	148	< .001	+ .08
Depression	.07	- .27	11.93	1	152	< .001		.01				.905	
HA	.02	- .15	9.91	1	438	.002	.10	- .31	8.24	2	145	< .001	+ .08
Depression	.07	- .27	11.93	1	152	< .001		- .10				.197	
CX	.02	.15	1.29	1	440	.01	.11	- .27	8.92	2	148	.001	+ .09
Depression	.07	- .27	11.93	1	152	< .001		.17				.029	
CE	.02	.13	7.87	1	441	.005	.09	- .26	7.65	2	150	.001	+ .07
Depression	.07	- .27	11.93	1	152	< .001		.13				.096	
CA	.06	.25	28.56	1	443	< .001	.14	- .29	12.06	2	150	< .001	+ .08
Depression	.07	- .27	11.93	1	152	< .001		.25				.001	
FX	.04	.21	8.69	1	199	.004	.18	- .33	6.75	2	60	.007	+ .14
Depression	.07	- .27	11.93	1	152	< .001		.26				.033	
AY	.05	.23	23.81	1	435	< .001	.11	- .28	9.31	2	147	< .001	+ .06
Depression	.07	- .27	11.93	1	152	< .001		.20				.011	
AD	.05	.23	23.09	1	430	< .001	.14	.26	11.49	2	144	.001	+ .07
Depression	.07	- .27	11.93	1	152	< .001		- .29				< .001	
ED	.01	.08	2.67	1	444	.10	.07	- .27	6.00	2	151	.001	+ .09
Depression	.07	- .27	11.93	1	152	< .001		.03				.723	

Note. df = degrees of freedom; *dfr* = residual degrees of freedom

Table 23.

Depression as a Mediator of Health Behaviors Predicting Sexual Satisfaction

Variables	Individual Models						Mediation Models						ΔR^2
	R^2	β	*F*	*df*	*dfr*	*p*	R^2	β	*F*	*df*	*dfr*	*p*	
HX	.01	.11	4.12	1	345	.043	.14	- .38	9.333	2	113	< .001	+ .13
Depression	.12	- .35	14.66	1	107	< .001		- .04				.674	
HE	.01	.11	4.36	1	346	.038	.15	- .36	1.307	2	114	< .001	+ .14
Depression	.12	- .35	14.66	1	107	< .001		.11				.192	
CX	.01	.10	3.47	1	347	.063	.16	- .40	1.574	2	114	< .001	+ .15
Depression	.12	- .35	14.66	1	107	< .001		.02				.793	
FX	.02	.13	2.70	1	151	.102	.16	- .40	4.223	2	45	.006	+ .14
Depression	.12	- .35	14.66	1	107	< .001		- .05				.725	
AY	.01	.09	2.85	1	344	.092	.15	- .37	9.466	2	112	< .001	+ .14
Depression	.12	- .35	14.66	1	107	< .001		.11				.232	
ET	.10	.10	3.49	1	349	.063	.14	- .37	9.336	2	115	< .001	+ .04
Depression	.12	- .35	14.66	1	107	< .001		.03				.735	

Note. *df* = degrees of freedom; *dfr* = residual degrees of freedom

Table 24.

Trait Anxiety as a Mediator of Health Behaviors Predicting Sexual Interest

Variables	Individual Models						Mediation Models						ΔR^2
	R^2	β	*F*	*df*	*dfr*	*p*	R^2	β	*F*	*df*	*dfr*	*p*	
TT	.01	.09	3.39	1	442	.07	.04	- .19	2.78	2	148	.023	+ .03
Trait anxiety	.04	- .19	5.59	1	152	.02		.05				.510	
XC	.04	.19	17.06	1	434	< .001	.03	- .17	2.53	2	147	.045	- .01
Trait anxiety	.04	- .19	5.59	1	152	.02		.04				.681	
XD	.02	.14	8.98	1	434	.003	.04	- .19	2.73	2	147	.021	+ .02
Trait anxiety	.04	- .19	5.59	1	152	.02		- .06				.452	
HX	.02	.13	6.99	1	436	.009	.05	- .20	3.52	2	146	.017	+ .03
Trait anxiety	.04	- .19	5.59	1	152	.02		.07				.387	
HE	.01	.09	3.52	1	438	.06	.05	- .22	3.77	2	148	.007	+ .04
Trait anxiety	.04	- .19	5.59	1	152	.02		.01				.898	
HA	.02	- .15	9.91	1	438	.002	.05	- .22	3.87	2	145	.009	+ .03
Trait anxiety	.04	- .19	5.59	1	152	.02		- .07				.397	
CX	.02	.15	1.29	1	440	.01	.07	- .18	5.58	2	148	.026	+ .05
Trait anxiety	.04	- .19	5.59	1	152	.02		.18				.027	
CE	.02	.13	7.87	1	441	.005	.05	- .18	4.02	2	150	.031	+ .03
Trait anxiety	.04	- .19	5.59	1	152	.02		.12				.136	
CA	.06	.25	28.56	1	443	< .001	.09	- .18	7.09	2	150	.027	+ .03
Trait anxiety	.04	- .19	5.59	1	152	.02		.22				.005	
FX	.04	.21	8.69	1	199	.004	.15	- .27	5.57	2	61	.025	+ .11
Trait anxiety	.04	- .19	5.59	1	152	.02		.25				.043	
AY	.05	.23	23.81	1	435	< .001	.07	- .18	5.08	2	147	.027	+ .03
Trait anxiety	.04	- .19	5.59	1	152	.02		.17				.039	
AD	.05	.23	23.09	1	430	< .001	.09	.22	6.96	2	144	.006	+ .04
Trait anxiety	.04	- .19	5.59	1	152	.02		- .19				.017	
ED	.01	.08	2.67	1	444	.10	.04	- .19	2.78	2	151	.022	+ .03
Trait anxiety	.04	- .19	5.59	1	152	.02		.00				.972	

Note. *df* = degrees of freedom; *dfr* = residual degrees of freedom

Table 25.

GAF Score as a Mediator of Health Behaviors Predicting Sexual Satisfaction

Variables	Individual Models						Mediation Models						ΔR^2
	R^2	β	*F*	*df*	*dfr*	*p*	R^2	β	*F*	*df*	*dfr*	*p*	
HX	.01	.11	4.12	1	345	.043	.10	.32	4.989	2	89	.002	+ .09
GAF score	.10	.32	1.71	1	94	.001		.00				.979	
HE	.01	.11	4.36	1	346	.038	.10	.29	4.919	2	91	.004	+ .09
GAF score	.10	.32	1.71	1	94	.001		.08				.445	
CX	.01	.10	3.47	1	347	.063	.11	.32	5.514	2	91	.002	+ .10
GAF score	.10	.32	1.71	1	94	.001		- .08				.428	
FX	.02	.13	2.70	1	151	.102	.07	.24	1.179	2	34	.158	+ .05
GAF score	.10	.32	1.71	1	94	.001		- .12				.489	
AY	.01	.09	2.85	1	344	.092	.09	.30	4.565	2	91	.003	+ .08
GAF score	.10	.32	1.71	1	94	.001		.00				.987	
EC	.10	.10	3.49	1	349	.063	.09	.30	4.752	2	92	.004	- .01
GAF score	.10	.32	1.71	1	94	.001		.05				.614	

Note. *df* = degrees of freedom; *dfr* = residual degrees of freedom

Table 26.

Body Image as a Mediator of Health Behaviors Predicting Sexual Interest

Variables	Individual Models						Mediation Models						ΔR^2
	R^2	β	*F*	*df*	*dfr*	*p*	R^2	β	*F*	*df*	*dfr*	*p*	
TT	.01	.09	3.39	1	442	.07	.08	.26	18.19	2	438	< .001	+ .07
Body image	.07	.27	33.94	1	446	.00		.08				.069	
XC	.04	.19	17.06	1	434	< .001	.10	.25	23.19	2	430	< .001	+ .06
Body image	.07	.27	33.94	1	446	.00		.15				.001	
XD	.02	.14	8.98	1	434	.003	.09	.26	2.24	2	430	< .001	+ .07
Body image	.07	.27	33.94	1	446	.00		.11				.022	
HX	.02	.13	6.99	1	436	.009	.08	.27	19.89	2	432	< .001	+ .06
Body image	.07	.27	33.94	1	446	.00		.07				.126	
HE	.01	.09	3.52	1	438	.06	.08	.27	17.87	2	434	< .001	+ .07
Body image	.07	.27	33.94	1	446	.00		.04				.462	
HA	.02	- .15	9.91	1	438	.002	.10	.27	22.80	2	434	< .001	+ .08
Body image	.07	.27	33.94	1	446	.00		- .14				.003	
CX	.02	.15	1.29	1	440	.01	.08	.25	19.55	2	436	< .001	+ .06
Body image	.07	.27	33.94	1	446	.00		.10				.033	
CE	.02	.13	7.87	1	441	.005	.10	.28	23.27	2	437	< .001	+ .08
Body image	.07	.27	33.94	1	446	.00		.12				.009	
CA	.06	.25	28.56	1	443	< .001	.13	.27	32.66	2	439	< .001	+ .07
Body image	.07	.27	33.94	1	446	.00		.23				< .001	
FX	.04	.21	8.69	1	199	.004	.09	.21	9.38	2	197	.003	+ .05
Body image	.07	.27	33.94	1	446	.00		.17				.016	
AY	.05	.23	23.81	1	435	< .001	.11	.25	26.58	2	431	< .001	+ .06
Body image	.07	.27	33.94	1	446	.00		.20				< .001	
AD	.05	.23	23.09	1	430	< .001	.11	.20	26.19	2	426	< .001	+ .06
Body image	.07	.27	33.94	1	446	.00		.25				< .001	
ED	.01	.08	2.67	1	444	.10	.08	.26	17.86	2	440	< .001	+ .07
Body image	.07	.27	33.94	1	446	.00		.06				.213	

Note. *df* = degrees of freedom; *dfr* = residual degrees of freedom

Table 27.

Body Image as a Mediator of Health Behaviors Predicting Sexual Satisfaction

Variables	Individual Models						Mediation Models						ΔR^2
	R^2	β	*F*	*df*	*dfr*	*p*	R^2	β	*F*	*df*	*dfr*	*p*	
HX	.01	.11	4.12	1	345	.043	.15	.37	28.846	2	341	< .001	+ .14
Body image	.13	.37	53.97	1	351	< .001		.03				.522	
HE	.01	.11	4.36	1	346	.038	.14	.37	27.862	2	342	< .001	+ .13
Body image	.13	.37	53.97	1	351	< .001		.04				.463	
CX	.01	.10	3.47	1	347	.063	.15	.38	29.962	2	343	< .001	+ .14
Body image	.13	.37	53.97	1	351	< .001		.01				.822	
FX	.02	.13	2.70	1	151	.102	.13	.34	11.196	2	149	< .001	+ .11
Body image	.13	.37	53.97	1	351	< .001		.05				.509	
AY	.01	.09	2.85	1	344	.092	.13	.35	25.591	2	340	< .001	+ .12
Body image	.13	.37	53.97	1	351	< .001		.05				.321	
EC	.10	.10	3.49	1	349	.063	.13	.36	25.907	2	345	< .001	+ .03
Body image	.13	.37	53.97	1	351	< .001		.04				.414	

Note. *df* = degrees of freedom; *dfr* = residual degrees of freedom

Table 28.

Covariates' Predictions of SQOL Outcomes

Variable	Outcome	β	R^2	*F*	*df*	*dfr*	*p*
Transplant Type	Satisfaction	.11	.01	4.57	1	346	.033
Pain	Satisfaction	- .10	.01	3.19	1	351	.075
Fertility Concerns	Satisfaction	- .08	.01	2.05	1	333	.153
ECOG	Satisfaction	- .12	.02	2.21	1	143	.139
QOL	Satisfaction	.24	.06	22.23	1	354	< .001
CH	Satisfaction	- .29	.09	32.49	1	345	< .001
Treatment Effects	Satisfaction	- .14	.02	6.61	1	348	.011
Transplant Type	Interest	.12	.02	6.58	1	440	.011
Pain	Interest	- .12	.02	6.60	1	444	.011
Fertility Concerns	Interest	.14	.02	8.57	1	422	.004
ECOG	Interest	.03	.00	.15	1	183	.704
QOL	Interest	.27	.07	34.80	1	449	< .001
CH	Interest	- .31	.10	46.06	1	437	< .001
Treatment Effects	Interest	- .23	.05	23.72	1	444	< .001

Note. *df* = degrees of freedom; *dfr* = residual degrees of freedom

Table 29.

Predictions of Sexual Satisfaction Controlling for Transplant Type

Predictor	Composite Model						ΔR^2	Overall *p*
	β	R^2	*F*	*df*	*dfr*	*p*		
TC	- .07	.02	3.01	2	340	.176	+ .02	.051
Type	.12					.033		
XC	.08	.02	2.90	2	334	.163	- .02	.056
Type	.11					.044		
AY	.07	.02	3.31	2	335	.184	+ .01	.038
Type	.11					.053		
AT	.09	.02	1.59	2	206	.193	+ .01	.207
Type	.08					.261		
EC	.09	.02	3.29	2	340	.117	- .08	.038
Type	.10					.056		
HX	--	.02	1.57	1	336	--	+ .01	.210
Type	--					--		
HE	--	.02	3.39	1	337	--	+ .01	.066
Type	--					--		
HL	--	.02	1.25	1	336	--	+ .02	.265
Type	--					--		

Note. For individual prediction models' data, refer to previous tables.
df = degrees of freedom; *dfr* = residual degrees of freedom

Table 30.

Predictions of Sexual Satisfaction Controlling for Pain

Predictor	Composite Model							
	β	R^2	*F*	*df*	*dfr*	*p*	Δ R^2	Overall *p*
TC	- .07	.01	2.35	2	346	.215	+ .01	.097
Pain	- .10					.074		
XC	.07	.01	2.12	2	340	.220	.00	.122
Pain	- .08					.120		
AY	.09	.02	3.04	2	340	.092	+ .01	.049
Pain	- .10					.074		
AT	.11	.02	2.28	2	209	.120	+ .01	.105
Pain	- .12					.095		
EC	.10	.02	2.98	2	345	.059	- .08	.052
Pain	- .08					.119		
HX	--	.01	3.84	1	341	--	+ .01	.051
Pain	--					--		
HE	--	.01	3.46	1	342	--	.00	.064
Pain	--					--		
CX	--	.02	3.99	2	342	--	+ .01	.019
Pain	--					--		

Note. For individual prediction models' data, refer to previous tables.
df = degrees of freedom; *dfr* = residual degrees of freedom

Table 31.

Predictions of Sexual Satisfaction Controlling for Fertility Concerns

Predictor	Composite Model							
	β	R^2	*F*	*df*	*dfr*	*p*	Δ R^2	Overall *p*
TC Fertility	- .06 - .07	.01	1.39	2	328	.308 .187	+ .01	.251
XC Fertility	.06 - .07	.01	1.40	2	323	.275 .216	.00	.248
AY Fertility	.09 - .07	.01	2.18	2	325	.113 .177	.00	.114
AT Fertility	.10 - .05	.01	1.17	2	202	.456 .150	.00	.313
EC Fertility	.10 - .06	.01	2.37	2	328	.078 .256	- .09	.095
HX Pain	-- --	.01	2.90	1	313	-- --	.00	.090
HE Pain	-- --	.01	2.92	1	324	-- --	.00	.088
CX Fertility	-- --	.02	3.36	2	325	-- --	+ .01	.036

Note. For individual prediction models' data, refer to previous tables.
df = degrees of freedom; *dfr* = residual degrees of freedom

Table 32.

Predictions of Sexual Satisfaction Controlling for Functional Status (Pre-Transplant; ECOG)

Predictor	Composite Model							
	β	R^2	*F*	*df*	*dfr*	*p*	Δ R^2	Overall *p*
TC	- .08	.03	1.77	2	139	.324	+ .03	.174
ECOG	- .14					.101		
XC	.14	.04	2.82	2	137	.094	+ .03	.063
ECOG	- .13					.142		
AY	.07	.02	1.14	2	138	.414	+ .01	.323
ECOG	- .10					.250		
AT	.13	.04	1.70	2	85	.235	+ .03	.190
ECOG	- .14					.203		
EC	.04	.02	1.16	2	141	.653	- .08	.318
ECOG	- .11					.180		
HX	--	.00	.02	1	138	--	- .01	.881
Pain	--					--		
HE	--	.02	2.89	1	139	--	+ .01	.092
Pain	--					--		
CW	--	.05	4.23	2	135	--	+ .05	.017
ECOG	--					--		

Note. For individual prediction models' data, refer to previous tables.
df = degrees of freedom; *dfr* = residual degrees of freedom

Table 33.

Predictions of Sexual Satisfaction Controlling for Overall Quality of Life

Predictor	Composite Model β	R^2	*F*	*df*	*dfr*	*p*	Δ R^2	Overall *p*
TC QOL	- .07 .24	.06	1.91	2	348	.182 < .001	+ .06	< .001
XC QOL	.04 .26	.07	13.53	2	342	.470 < .001	+ .06	< .001
AY QOL	.04 .23	.06	1.64	2	343	.445 < .001	+ .05	< .001
AT QOL	.08 .24	.06	7.11	2	211	.248 .001	+ .05	.001
HX Pain	-- --	.06	2.20	1	344	-- --	+ .05	.139
HE Pain	-- --	.05	1.93	1	345	-- --	+ .04	.165
EC QOL	.08 .25	.07	13.76	2	348	.139 < .001	- .03	< .001

Note. For individual prediction models' data, refer to previous tables.
df = degrees of freedom; *dfr* = residual degrees of freedom

Table 34.

Predictions of Sexual Satisfaction Controlling for Current Health

Predictor	Composite Model						ΔR^2	Overall *p*
	β	R^2	*F*	*df*	*dfr*	*p*		
TC Health	- .05 - .29	.09	16.84	2	339	.311 < .001	+ .09	< .001
XC Health	.01 - .30	.09	16.17	2	335	.909 < .001	+ .08	< .001
AY Health	.03 - .28	.09	15.72	2	335	.521 < .001	+ .08	< .001
AT Health	.09 - .30	.10	11.04	2	207	.177 < .001	+ .09	< .001
HX Pain	-- --	.09	1.94	2	338	-- --	+ .08	.146
HE Pain	-- --	.08	.83	2	340	-- --	+ .07	.438
EC Health	.05 - .27	.08	14.98	2	339	.364 < .001	- .02	< .001

Note. *df* = degrees of freedom; *dfr* = residual degrees of freedom

Table 35.

Predictions of Sexual Satisfaction Controlling for Perception of Treatment Effects' Severity

Predictor	Composite Model						ΔR^2	Overall *p*
	β	R^2	*F*	*df*	*dfr*	*p*		
TC Effects	- .06 - .13	.02	3.65	2	342	.272 .015	+ .02	.027
XC Effects	.07 - .12	.02	3.33	2	336	.207 .028	+ .01	.037
AY Effects	.07 - .15	.03	4.95	2	339	.233 .007	+ .02	.008
AT Effects	.10 - .09	.02	2.11	2	209	.143 .184	+ .01	.124
EC Effects	.10 - .12	.02	4.22	2	343	.076 .031	- .08	.015
HX Pain	-- --	.02	2.63	1	338	-- --	+ .01	.106
HE Pain	-- --	.02	2.91	1	339	-- --	+ .01	.089
CX Effects	-- --	.03	3.60	2	339	-- --	+ .02	.028

Note. For individual prediction models' data, refer to previous tables.
df = degrees of freedom; *dfr* = residual degrees of freedom

Table 36.

Predictions of Sexual Interest Controlling for Transplant Type

Predictor	Composite Model				ΔR^2	Overall *p*
	R^2	*F*	*df*	*dfr*		
XD Type	.03	9.28	1	424	+ .01	.002
HX Type	.02	3.88	1	426	.00	.050
HA Type	.03	5.06	2	427	+ .01	.007
CX Type	.04	5.98	2	429	+ .02	.003
CE Type	.03	4.63	2	430	+ .03	.010
CA Type	.06	8.68	3	432	.00	< .001
FX Type	.05	7.42	1	195	+ .01	.007

Note. For individual prediction models' data, refer to previous tables.
df = degrees of freedom; *dfr* = residual degrees of freedom

Table 37.

Predictions of Sexual Interest Controlling for Pain

Predictor	Composite Model β	R^2	*F*	*df*	*dfr*	*p*	Δ R^2	Overall *p*
XC Pain	.18 - .11	.05	11.16	2	429	< .001 .025	+ .01	< .001
XD Pain	-- --	.03	8.22	1	429	-- --	+ .01	.004
AY Pain	.22 - .12	.06	14.54	2	429	< .001 .011	+ .01	< .001
HX Pain	-- --	.02	6.17	1	431	-- --	.00	.013
HA Pain	-- --	.04	5.63	2	432	-- --	+ .02	.004
CX Pain	-- --	.04	7.60	2	434	-- --	+ .02	.001
CE Pain	-- --	.03	5.15	2	436	-- --	+ .01	.006
CA Pain	-- --	.07	9.41	3	436	-- --	+ .01	< .001
FX Pain	-- --	.03	8.46	1	197	-- --	- .01	.004

Note. For individual prediction models' data, refer to previous tables.
df = degrees of freedom; *dfr* = residual degrees of freedom

Table 38.

Predictions of Sexual Interest Controlling for Fertility Concerns

Predictor	Composite Model						ΔR^2	Overall *p*
	β	R^2	*F*	*df*	*dfr*	*p*		
XC	.18	.05	11.39	2	408	< .001	+ .01	< .001
Fertility	.14					.005		
XD	--	.03	6.99	1	408	--	+ .01	.009
Fertility	--					--		
AY	.23	.08	16.95	2	410	< .001	+ .03	< .001
Fertility	.16					.001		
HX	--	.03	5.53	1	408	--	+ .01	.019
Fertility	--					--		
HE	--	.03	3.58	1	410	--	+ .01	.059
Fertility	--					--		
HA	--	.04	4.76	2	410	--	+ .02	.009
Fertility	--					--		
CX	--	.04	5.64	2	412	--	+ .02	.004
Fertility	--					--		
CE	--	.03	4.14	2	412	--	+ .01	.017
Fertility	--					--		
CA	--	.07	9.38	3	413	--	+ .01	< .001
Fertility	--					--		
FX	--	.05	1.00	1	187	--	+ .01	.002
Fertility	--					--		

Note. For individual prediction models' data, refer to previous tables.
df = degrees of freedom; *dfr* = residual degrees of freedom

Table 39.

Predictions of Sexual Interest Controlling for Functional Status (Pre-Transplant; ECOG)

Predictor	Composite Model β	R^2	*F*	*df*	*dfr*	*p*	Δ R^2	Overall *p*
XD	--	.00	.27	1	177	--	+ .01	.604
ECOG	--					--		
HX	--	.01	.94	1	176	--	+ .01	.333
ECOG	--					--		
HA	--	.01	.47	2	175	--	+ .01	.629
ECOG	--					--		
AY	.17	.03	2.80	2	177	.021	- .02	.064
ECOG	.05					.542		
CX	--	.03	4.58	2	176	--	+ .01	.012
ECOG	--					--		
CE	--	.05	4.58	2	176	--	+ .03	.012
ECOG	--					--		
CA	--	.04	3.56	3	178	--	+ .02	.016
ECOG	--					--		
FX	--	.07	6.71	1	69	--	+ .03	.012
ECOG	--					--		
FL	--	.53	11.61	1	20	--	+ .52	.003
ECOG	--					--		

Note. For individual prediction models' data, refer to previous tables.
df = degrees of freedom; *dfr* = residual degrees of freedom

Table 40.

Predictions of Sexual Interest Controlling for Overall Quality of Life

Predictor	Composite Model						ΔR^2	Overall *p*
	β	R^2	*F*	*df*	*dfr*	*p*		
XC	.16	.09	22.39	2	433	.001	+ .05	< .001
QOL	.34					< .001		
XD	--	.08	5.37	1	433	--	+ .06	.021
QOL	--					--		
AY	.18	.11	27.11	2	434	< .001	+ .06	< .001
QOL	.25					< .001		
HX	--	.08	3.96	1	435	--	+ .06	.047
QOL	--					--		
HA	--	.08	4.07	2	436	--	+ .06	.018
QOL	--					--		
CX	--	.09	5.35	2	438	--	+ .07	.005
QOL	--					--		
CE	--	.09	2.78	2	439	--	+ .07	.063
QOL	--					--		
CA	--	.11	7.44	3	440	--	+ .05	< .001
QOL	--					--		
FX	--	.09	6.48	1	198	--	+ .05	.012
QOL	--					--		

Note. For individual prediction models' data, refer to previous tables.
df = degrees of freedom; *dfr* = residual degrees of freedom

Table 41.

Predictions of Sexual Interest Controlling for Current Health

Predictor	Composite Model							
	β	R^2	*F*	*df*	*dfr*	*p*	Δ R^2	Overall *p*
XC	.13	.12	28.29	2	423	.007	+ .08	< .001
Health	- .29					< .001		
XD	--	.11	4.02	1	423	--	+ .09	.045
Health	--					--		
AY	- .29	.14	33.39	2	423	< .001	+ .09	< .001
Health	.18					< .001		
HX	--	.10	2.74	1	429	--	+ .08	.099
Health	--					--		
HA	--	.10	3.69	2	429	--	+ .08	.026
Health	--					--		
CX	--	.10	4.03	2	430	--	+ .08	.018
Health	--					--		
CE	--	.11	2.86	2	431	--	+ .09	.058
Health	--					--		
CA	--	.13	7.03	3	432	--	+ .07	< .001
Health	--					--		
FX	--	.14	3.96	1	194	--	+ .10	.048
Health	--					--		

Note. For individual prediction models' data, refer to previous tables.
df = degrees of freedom; *dfr* = residual degrees of freedom

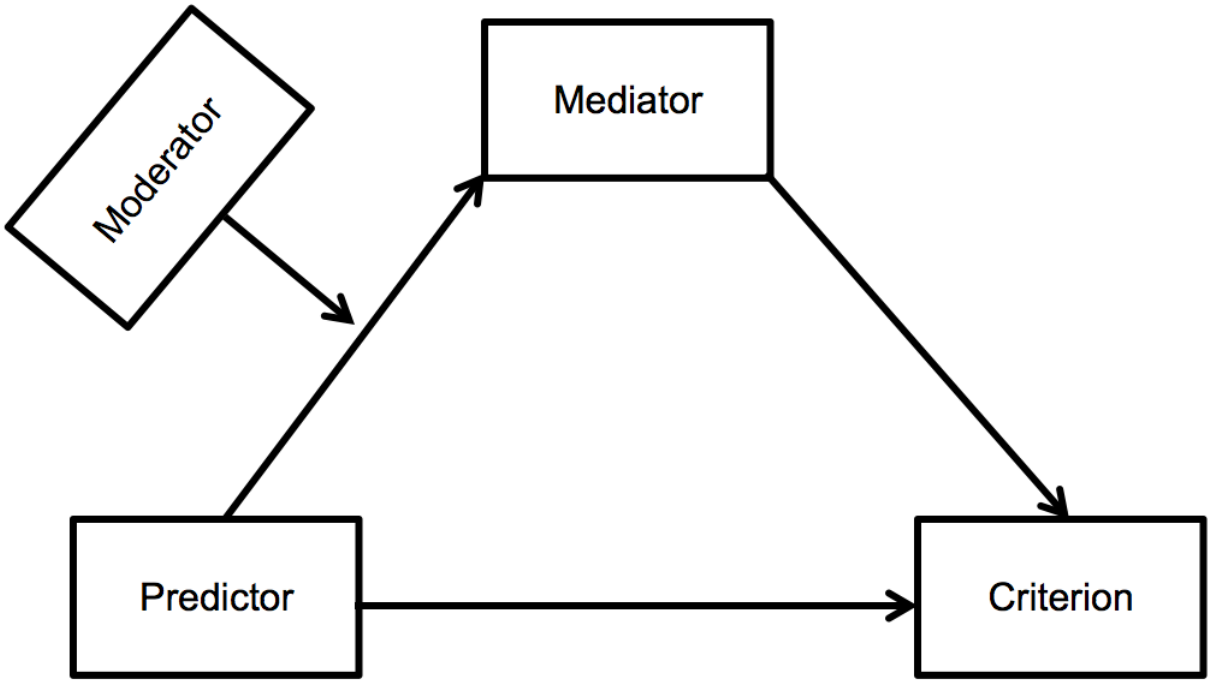
Table 42.

Predictions of Sexual Interest Controlling for Perceptions of Treatment Effects' Severity

Predictor	Composite Model							
	β	R^2	*F*	*df*	*dfr*	*p*	Δ R^2	Overall *p*
TC Effects	.06 - .22	.05	12.01	2	437	.184 < .001	+ .05	< .001
XC Effects	.19 - .22	.09	2.48	2	428	< .001 < .001	+ .05	< .001
XD Effects	-- --	.07	1.11	1	428	-- --	+ .05	.002
AY Effects	.19 - .20	.09	21.07	2	430	< .001 < .001	+ .04	< .001
HX Effects	-- --	.05	4.48	1	430	-- --	+ .03	.035
HA Effects	-- --	.06	4.07	2	431	-- --	+ .04	.018
CX Effects	-- --	.08	6.91	2	433	-- --	+ .06	.001
CE Effects	-- --	.07	4.37	2	434	-- --	+ .05	.013
CA Effects	-- --	.09	7.50	3	435	-- --	+ .03	< .001
FX Effects	-- --	.08	8.31	1	194	-- --	+ .04	.004

Note. For individual prediction models' data, refer to previous tables.
df = degrees of freedom; *dfr* = residual degrees of freedom

Figure 1. Proposed moderated mediation model.



Appendix A

MAYO CLINIC

Principal Investigator Notification:

From: Mayo Clinic IRB
To: Shawna Ehlers
CC: Stephen Ansell
Gail Bierbaum
Tabetha Brockman
James Cerhan
Paul Decker
Angela Dispenzieri
Jon Ebbert
Shawna Ehlers
Dennis Gastineau
William Hogan
Christine Hughes
Lise Nes
Luis Porrata
Christi Preiss

Re: **Continuing Review #:** PR08-006915-03
Title: The Role of Health Behaviors in Hematopoietic Stem Cell Transplantation

IRBe Protocol Version: 0.05
IRBe Version Date: 12/8/2011 8:50 AM

IRB Approval Date: 12/8/2011
IRB Expiration Date: 12/7/2012

Continuation of the above referenced study is approved by expedited review procedures (45 CFR 46.110, item 5, 7). The Reviewer determined the research continues to pose no more than minimal risk to subjects. The Reviewer determined that this research continues to satisfy the requirements of 45 CFR 46.111. The written consent form was reviewed and approved with revisions and in conjunction with a modification (Mod08-006915-17).

Appendix A (continued)

AS THE PRINCIPAL INVESTIGATOR OF THIS PROJECT, YOU ARE RESPONSIBLE FOR THE FOLLOWING RELATING TO THIS STUDY (as they apply):
(1) Use of only IRB approved materials which are located under the documents tab of the IRBe workspace. Materials include consent forms, questionnaires, letters, advertisements, etc.
(2) Submission to the IRB of any modifications and supporting documents for review and approval prior to initiation of the changes.
(3) Submission to the IRB of all unanticipated problems involving risks to subjects or others (UPIRTSO).
(4) Compliance with Mayo Clinic Institutional Policies.

Mayo Clinic Institutional Reviewer

Appendix A (continued)

MAYO CLINIC

Principal Investigator Notification:

From: Mayo Clinic IRB
To: Shawna Ehlers
CC: Stephen Ansell
Gail Bierbaum
Tabetha Brockman
James Cerhan
Paul Decker
Angela Dispenzieri
Jon Ebbert
Shawna Ehlers
Dennis Gastineau
William Hogan
Christine Hughes
Lise Nes
Luis Porrata
Christi Preiss

Re: **IRB Modification #:** Mod08-006915-18
Title: The Role of Health Behaviors in Hematopoietic Stem Cell Transplantation

IRBe Protocol Version:
IRBe Version Date:
Modification Approval Date: 6/21/2012

A personnel modification (Mod08-006915-18) for the above referenced study is approved by expedited review procedures. The modification constitutes a minor change to previously approved research, and therefore was eligible for expedited review in accordance with 45 CFR 46.110 (b)(2). The Reviewer determined the modification(s) pose no more than minimal risk to subjects.

A personnel modification for the above referenced study has been submitted electronically. The following personnel changes have been made.

Appendix A (continued)

People Added	Location	Role	Edit	Consent	Notify	LabResults
Carrie Bronars	Mayo Clinic in Rochester, MN	Co-Investigator	no	no	no	no
Keagan Mcpherson	Mayo Clinic in Rochester, MN	Study Assistant	no	no	no	no

Mayo Clinic Institutional Reviewer

Appendix B

MINNESOTA STATE UNIVERSITY
MANKATO

October 3, 2012

Dear Eric Sprankle:

Re: IRB Proposal entitled "[383228-1] Role of Health Behaviors in Sexual Quality of Life Among Survivors of Hematopoietic Stem Cell Transplantion"
Review Level: Level *I*

Your IRB Proposal has been approved as of October 3, 2012. On behalf of the Minnesota State University, I wish you success with your study. Remember that you must seek approval for any changes in your study, its design, funding source, consent process, or any part of the study that may affect participants in the study. Should any of the participants in your study suffer a research-related injury or other harmful outcome, you are required to report them to the IRB as soon as possible.

The approval of your study is for one calendar year less a day from the approval date. When you complete your data collection or should you discontinue your study, you must notify the IRB. Please include your log number with any correspondence with the IRB.

This approval is considered final when the full IRB approves the monthly decisions and active log. The IRB reserves the right to review each study as part of its continuing review process. Continuing reviews are usually scheduled. However, under some conditions the IRB may choose not to announce a continuing review. If you have any questions, feel free to contact me at irb@mnsu.edu or 507-389-5102.

Cordially,

Mary Hadley, Ph.D.
IRB Coordinator

Sarah Sifers, Ph.D.
IRB Co-Chair

Appendix B (continued)

Richard Auger, Ph.D.
IRB Co-Chair

This letter has been electronically signed in accordance with all applicable regulations, and a copy is retained within Minnesota State University's records.

Appendix C

Department of Psychiatry and Psychology
Behavioral Health Research Program
Mayo Clinic Rochester
200 First St. SW
Rochester, MN 55905

October 2, 2012

Institutional Review Board
Minnesota State University, Mankato
Mankato, Minnesota

Re:
KL2: The Role of Health Behaviors in Hematopoietic Stem Cell Transplantation

Dear Colleagues,

This letter is to document permission granted to Keagan McPherson to utilize data on SQOL among hematopoietic stem cell transplant patients within the above protocol for his dissertation. This data was collected as part of a larger NIH-funded study examining behavioral predictors of transplant outcomes, including quality of life, and I will supervise its use. These procedures were approved by the Mayo Clinic IRB (08-006915).

I serve as the Mayo Clinic Principal Investigator for the study. Please contact me if you have any questions.

Sincerely,

Appendix C (continued)

Shawna L. Ehlers, Ph.D., A.B.P.P., L.P.
Assistant Professor of Psychology
Department of Psychiatry and Psychology
Mayo Clinic Rochester
ehlers.shawna@mayo.edu
Phone: (507) 284-5849
Fax: (507) 284-4158

Appendix D

PRE-TRANSPLANT QUALITY OF LIFE QUESTIONNAIRE

(Completed during first visit at the transplant center, 1st Questionnaire)

Name: _____

Mayo Clinic # _____

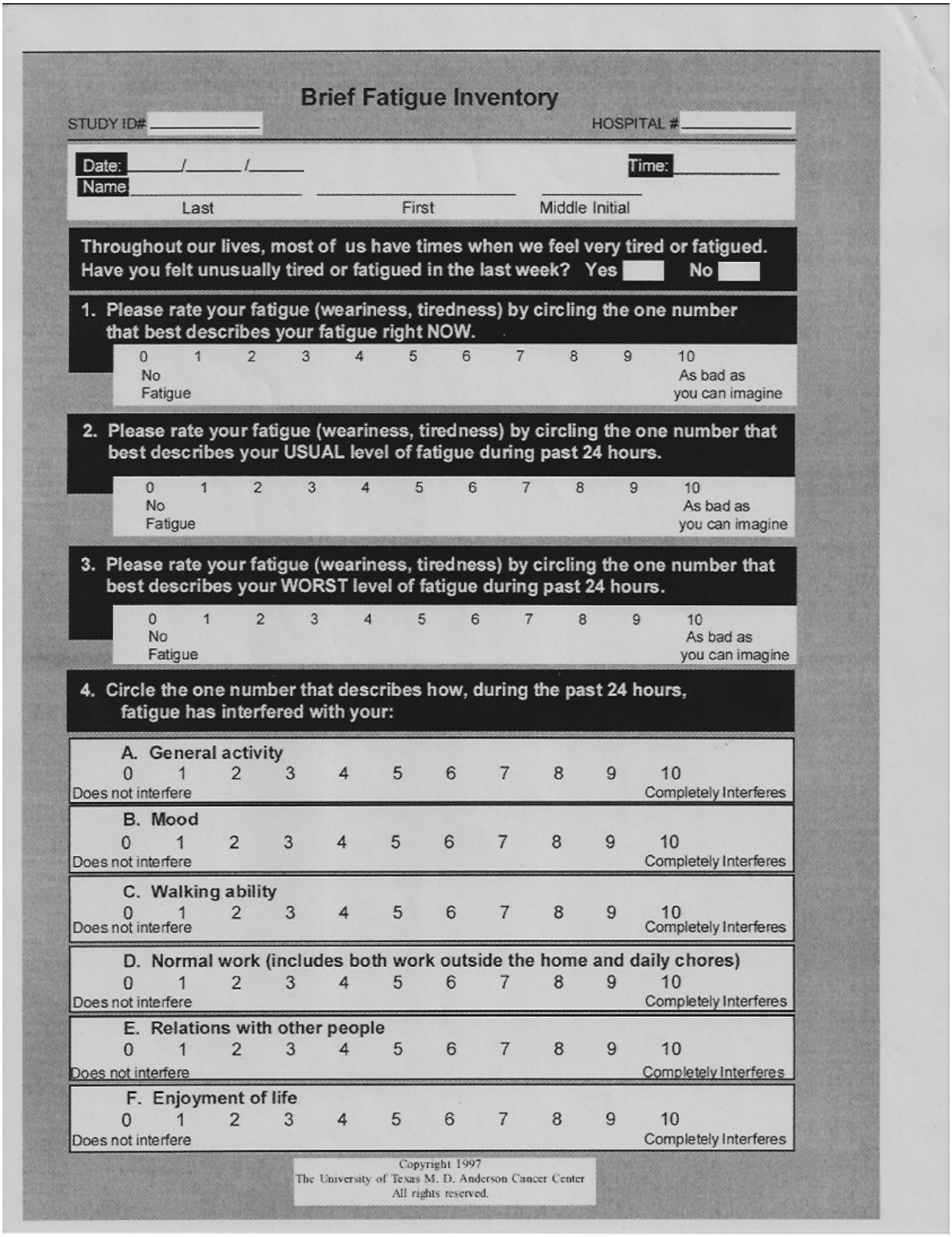
Date: ___/___/_____

This questionnaire allows our team to better understand and care for you as an individual person. Therefore, it's important that you (the patient) fill it out to the best of your ability without help from others' opinions. It takes most people 15-30 minutes to complete. If you have any questions please call Dr. Ehlers' office at 507-284-4431.

Please note:

- **There are no right or wrong answers.**
- Don't spend a lot of time on any one question.
- Try to answer each question separately- without comparing it to other questions.
- Please answer each question as honestly as you can, giving your best answer.
- Choose only 1 answer for each question.

Appendix D (continued)



Brief Fatigue Inventory

STUDY ID# _____ HOSPITAL # _____

Date: ____/____/____ Time: _____

Name _____ _____ _____

Last First Middle Initial

Throughout our lives, most of us have times when we feel very tired or fatigued. Have you felt unusually tired or fatigued in the last week? Yes ☐ No ☐

1. Please rate your fatigue (weariness, tiredness) by circling the one number that best describes your fatigue right NOW.

0 1 2 3 4 5 6 7 8 9 10
No Fatigue — As bad as you can imagine

2. Please rate your fatigue (weariness, tiredness) by circling the one number that best describes your USUAL level of fatigue during past 24 hours.

0 1 2 3 4 5 6 7 8 9 10
No Fatigue — As bad as you can imagine

3. Please rate your fatigue (weariness, tiredness) by circling the one number that best describes your WORST level of fatigue during past 24 hours.

0 1 2 3 4 5 6 7 8 9 10
No Fatigue — As bad as you can imagine

4. Circle the one number that describes how, during the past 24 hours, fatigue has interfered with your:

A. General activity
0 1 2 3 4 5 6 7 8 9 10
Does not interfere — Completely Interferes

B. Mood
0 1 2 3 4 5 6 7 8 9 10
Does not interfere — Completely Interferes

C. Walking ability
0 1 2 3 4 5 6 7 8 9 10
Does not interfere — Completely Interferes

D. Normal work (includes both work outside the home and daily chores)
0 1 2 3 4 5 6 7 8 9 10
Does not interfere — Completely Interferes

E. Relations with other people
0 1 2 3 4 5 6 7 8 9 10
Does not interfere — Completely Interferes

F. Enjoyment of life
0 1 2 3 4 5 6 7 8 9 10
Does not interfere — Completely Interferes

Appendix D (continued)

PAIN: Circle the number best representing your pain.

1 Please rate your pain right **now**.

0	1	2	3	4	5	6	7	8	9	10
No pain					Moderate pain					Worst possible pain

2 Please rate your **average** pain in the past **1 week**.

0	1	2	3	4	5	6	7	8	9	10
No pain					Moderate pain					Worst possible pain

3 Please rate your **worst** pain in the past **1 week**.

0	1	2	3	4	5	6	7	8	9	10
No pain					Moderate pain					Worst possible pain

Appendix D (continued)

	FACT: How true has each statement been for you in the past week?	Not at all	A little bit	Somewhat	Quite a bit	Very much
	PHYSICAL WELL-BEING					
1	I have a lack of energy.	0	1	2	3	4
2	I have nausea.	0	1	2	3	4
3	Because of my physical condition, I have trouble meeting the needs of my family.	0	1	2	3	4
4	I have pain.	0	1	2	3	4
5	I am bothered by side effects of treatment.	0	1	2	3	4
6	I feel ill.	0	1	2	3	4
7	I am forced to spend time in bed.	0	1	2	3	4
	SOCIAL/FAMILY WELL-BEING					
1	I feel close to my friends.	0	1	2	3	4
2	I get emotional support from my family.	0	1	2	3	4
3	I get support from my friends.	0	1	2	3	4
4	My family has accepted my illness.	0	1	2	3	4
5	I am satisfied with family communication about my illness.	0	1	2	3	4
6	I feel close to my partner (or the person who is my main support).	0	1	2	3	4
7	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box* ☐ *and go to the next section.*					
	I am satisfied with my sex life.	0	1	2	3	4
	EMOTIONAL WELL-BEING					
1	I feel sad.	0	1	2	3	4
2	I am satisfied with how I am coping with my illness.	0	1	2	3	4
3	I am losing hope in the fight against my illness.	0	1	2	3	4
4	I feel nervous.	0	1	2	3	4
5	I worry about dying.	0	1	2	3	4
6	I worry that my condition will get worse.	0	1	2	3	4
	FUNCTIONAL WELL-BEING					
1	I am able to work (include work at home).	0	1	2	3	4
2	My work (include work at home) is fulfilling.	0	1	2	3	4
3	I am able to enjoy life.	0	1	2	3	4
4	I have accepted my illness.	0	1	2	3	4
5	I am sleeping well.	0	1	2	3	4
6	I am enjoying the things I usually do for fun.	0	1	2	3	4
7	I am content with the quality of my life right now.	0	1	2	3	4

Appendix D (continued)

MHLOC: HEALTH BELIEFS: Each item below is a belief statement about your medical condition, with which you may agree or disagree. Please **circle the number that represents the extent to which you agree or disagree with that statement**. The more you agree with a statement, the higher the number you circle. This is a measure of your personal beliefs- there are no right or wrong answers.

		Strongly Disagree	Moderately Disagree	Slightly Disagree	Slightly Agree	Moderately Agree	Strongly Agree
1	If my condition worsens, it is my own behavior which determines how soon I will feel better again.	1	2	3	4	5	6
2	As to my condition, what will be will be.	1	2	3	4	5	6
3	If I see my doctor regularly, I am less likely to have problems with my condition.	1	2	3	4	5	6
4	Most things that affect my condition happen to me by chance.	1	2	3	4	5	6
5	Whenever my condition worsens, I should consult a medically trained professional.	1	2	3	4	5	6
6	I am directly responsible for my condition getting better or worse.	1	2	3	4	5	6
7	Other people play a big role in whether my condition improves, stays the same, or gets worse.	1	2	3	4	5	6
8	Whatever goes wrong with my condition is my own fault.	1	2	3	4	5	6
9	Luck plays a big part in determining how my condition improves.	1	2	3	4	5	6
10	In order for my condition to improve, it is up to other people to see that the right things happen.	1	2	3	4	5	6
11	Whatever improvement occurs with my condition is largely a matter of good fortune.	1	2	3	4	5	6
12	The main thing which affects my condition is what I myself do.	1	2	3	4	5	6
13	I deserve the credit when my condition improves and the blame when it gets worse.	1	2	3	4	5	6
14	Following doctor's orders to the letter is the best way to keep my condition from getting any worse.	1	2	3	4	5	6
15	If my condition worsens, it's a matter of fate.	1	2	3	4	5	6
16	If I am lucky, my condition will get better.	1	2	3	4	5	6
17	If my condition takes a turn for the worse, it is because I have not been taking proper care of myself.	1	2	3	4	5	6
18	The type of help I receive from other people determines how soon my condition improves.	1	2	3	4	5	6

Appendix D (continued)

BFI: DESCRIBE SELF: Please consider how you see your feelings, behaviors, and preferences. For example, do you see yourself as someone who *likes to spend time with others*? **For each of the items given below**, indicate whether you see it as **true** (characteristic) of yourself or as **not true** (not characteristic) of yourself. **Select the appropriate number** from the rating scale below for each statement. Then **write it in the blank space** in front of the statement.

Very Untrue	Somewhat Untrue	Neither True nor Untrue	Somewhat True	Very True
1	2	3	4	5

I See Myself as Someone Who...		
____ 1. Is talkative	____ 16. Values artistic, aesthetic experiences	____ 32. Likes to plan things
____ 2. Is lazy at times	____ 17. Is relaxed, handles stress well	____ 33. Has a forgiving nature
____ 3. Tends to find fault with others	____ 18. Is sometimes shy, inhibited	____ 34. Gets nervous easily
____ 4. Is emotionally stable, not easily upset	____ 19. Is curious about many different things	____ 35. Tends to be disorganized
____ 5. Does a thorough job	____ 20. Is considerate and kind to almost everyone	____ 36. Likes to reflect, play with ideas
____ 6. Is inventive	____ 21. Is full of energy	____ 37. Worries a lot
____ 7. Is depressed, blue	____ 22. Does things efficiently	____ 38. Has few artistic interests
____ 8. Is not very assertive	____ 23. Gets into quarrels	____ 39. Has an active imagination
____ 9. Is original, comes up with new ideas	____ 24. Remains calm in tense situations	____ 40. Likes to cooperate with others
____ 10. Can be cold and aloof	____ 25. Is a reliable worker	____ 41. Tends to be quiet
____ 11. Is reserved	____ 26. Prefers work that is routine and simple	____ 42. Is easily distracted
____ 12. Perseveres until the task is finished	____ 27. Can be tense	____ 43. Is generally trusting
____ 13. Likes to be helpful	____ 28. Is outgoing, sociable	____ 44. Is sophisticated in art, music or literature
____ 14. Can be moody	____ 29. Is ingenious, a quick thinker	
____ 15. Can be somewhat careless	____ 30. Is sometimes rude to others	
	____ 31. Generates a lot of enthusiasm	

Appendix D (continued)

COPE: COPING STYLE: Please indicate how you have tried to cope with your illness. It does not matter if it was helpful or not. Make your answers as true **for you** as you can.

		I haven't been doing this at all	I've been doing this a little bit	I've been doing this a medium amount	I've been doing this a lot
1	I've been turning to work or other activities to take my mind off things.	1	2	3	4
2	I've been concentrating my efforts on doing something about the situation I'm in.	1	2	3	4
3	I've been saying to myself "this isn't real."	1	2	3	4
4	I've been using alcohol or other drugs to make myself feel better.	1	2	3	4
5	I've been getting emotional support from others.	1	2	3	4
6	I've been giving up trying to deal with it.	1	2	3	4
7	I've been taking action to try to make the situation better.	1	2	3	4
8	I've been refusing to believe that it has happened.	1	2	3	4
9	I've been saying things to let my unpleasant feelings escape.	1	2	3	4
10	I've been getting help and advice from other people.	1	2	3	4
11	I've been using alcohol or other drugs to help me get through it.	1	2	3	4
12	I've been trying to see it in a different light, to make it seem more positive.	1	2	3	4
13	I've been criticizing myself.	1	2	3	4
14	I've been trying to come up with a strategy about what to do.	1	2	3	4
15	I've been getting comfort and understanding from someone.	1	2	3	4
16	I've been giving up the attempt to cope.	1	2	3	4
17	I've been looking for something good in what is happening.	1	2	3	4
18	I've been making jokes about it.	1	2	3	4
19	I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.	1	2	3	4
20	I've been accepting the reality of the fact that it has happened.	1	2	3	4
21	I've been expressing my negative feelings.	1	2	3	4
22	I've been trying to find comfort in my religion or spiritual beliefs.	1	2	3	4
23	I've been trying to get advice or help from other people about what to do.	1	2	3	4
24	I've been learning to live with it.	1	2	3	4
25	I've been thinking hard about what steps to take.	1	2	3	4
26	I've been blaming myself for things that happened.	1	2	3	4
27	I've been praying or meditating.	1	2	3	4
28	I've been making fun of the situation.	1	2	3	4

Appendix D (continued)

	BF: Having had a serious illness…	Not at all	A little	Moderately	Quite a bit	Extremely
1	has lead me to be more accepting of things.	1	2	3	4	5
2	has taught me how to adjust to things I cannot change.	1	2	3	4	5
3	has helped me take things as they come.	1	2	3	4	5
4	has brought my family closer together.	1	2	3	4	5
5	has made me more sensitive to family issues.	1	2	3	4	5
6	has taught me that everyone has a purpose in life.	1	2	3	4	5
7	has shown me that all people need to be loved.	1	2	3	4	5
8	has made me realize the importance of planning for my family's future.	1	2	3	4	5
9	has made me more aware and concerned for the future of all human beings.	1	2	3	4	5
10	has taught me to be patient.	1	2	3	4	5
11	has led me to deal better with stress and problems.	1	2	3	4	5
12	has led me to meet people who have become some of my best friends.	1	2	3	4	5
13	has contributed to my overall emotional and spiritual growth.	1	2	3	4	5
14	has helped me become more aware of the love and support available from other people.	1	2	3	4	5
15	has helped me realize who my real friends are.	1	2	3	4	5
16	has helped me become more focused on priorities, with a deeper sense of purpose in life.	1	2	3	4	5
17	has helped me become a stronger person, more able to cope effectively with future life challenges.	1	2	3	4	5

Appendix D (continued)

	NE: EXPRESSIVITY: Please indicate how much you agree or disagree with the following statements.	Strongly Disagree			Neutral			Strongly Agree
1	People often do not know what I am feeling.	1	2	3	4	5	6	7
2	It is difficult for me to hide my fear.	1	2	3	4	5	6	7
3	I've learned it is better to suppress my anger than to show it.	1	2	3	4	5	6	7
4	No matter how nervous or upset I am, I tend to keep a calm exterior.	1	2	3	4	5	6	7
5	Whenever I feel negative emotions, people can easily see exactly what I am feeling.	1	2	3	4	5	6	7
6	What I'm feeling is written all over my face.	1	2	3	4	5	6	7

	PSC: STYLE: Please indicate how much these statements are like you.	Not at all like me	A little like me	Somewhat like me	A lot like me
1	I'm concerned about my style of doing things.	0	1	2	3
2	I care a lot about how I present myself to others.	0	1	2	3
3	I'm self-conscious about the way I look.	0	1	2	3
4	I usually worry about making a good impression.	0	1	2	3
5	Before I leave my house, I check how I look.	0	1	2	3
6	I'm concerned about what other people think of me.	0	1	2	3
7	I'm usually aware of my appearance.	0	1	2	3

Please list any **comments** about this questionnaire (Examples: What was the hardest part of filling it out? Was there a question you didn't like?).

Appendix E

Q2

PRE-TRANSPLANT HEALTH PSYCHOLOGY QUESTIONNAIRE

(Completed during W-11 Evaluation, 2nd Questionnaire)

Name: _____

Mayo Clinic # _____

Date: ___/___/_____

This questionnaire allows our team to better understand and care for you as an individual person. Therefore, it's important that you (the patient) fill it out to the best of your ability without help from others' opinions. It takes most people 15-30 minutes to complete. You and your provider will discuss your answers.

Please note:

- **There are no right or wrong answers.**
- Don't spend a lot of time on any one question.
- Try to answer each question separately- without comparing it to other questions.
- Please answer each question as honestly as you can, giving your best answer.
- Choose only 1 answer for each question.

Appendix E (continued)

BDI-II

Date:

Name: _____ Marital Status: _____ Age: _____ Sex: _____

Occupation: _____ Education: _____

Instructions: This questionnaire consists of 21 groups of statements. Please read each group of statements carefully, and then pick out the **one statement** in each group that best describes the way you have been feeling during the **past two weeks, including today**. Circle the number beside the statement you have picked. If several statements in the group seem to apply equally well, circle the highest number for that group. Be sure that you do not choose more than one statement for any group, including Item 16 (Changes in Sleeping Pattern) or Item 18 (Changes in Appetite).

1. Sadness
- 0 I do not feel sad.
- 1 I feel sad much of the time.
- 2 I am sad all the time.
- 3 I am so sad or unhappy that I can't stand it.

2. Pessimism
- 0 I am not discouraged about my future.
- 1 I feel more discouraged about my future than I used to be.
- 2 I do not expect things to work out for me.
- 3 I feel my future is hopeless and will only get worse.

3. Past Failure
- 0 I do not feel like a failure.
- 1 I have failed more than I should have.
- 2 As I look back, I see a lot of failures.
- 3 I feel I am a total failure as a person.

4. Loss of Pleasure
- 0 I get as much pleasure as I ever did from the things I enjoy.
- 1 I don't enjoy things as much as I used to.
- 2 I get very little pleasure from the things I used to enjoy.
- 3 I can't get any pleasure from the things I used to enjoy.

5. Guilty Feelings
- 0 I don't feel particularly guilty.
- 1 I feel guilty over many things I have done or should have done.
- 2 I feel quite guilty most of the time.
- 3 I feel guilty all of the time.

6. Punishment Feelings
- 0 I don't feel I am being punished.
- 1 I feel I may be punished.
- 2 I expect to be punished.
- 3 I feel I am being punished.

7. Self-Dislike
- 0 I feel the same about myself as ever.
- 1 I have lost confidence in myself.
- 2 I am disappointed in myself.
- 3 I dislike myself.

8. Self-Criticalness
- 0 I don't criticize or blame myself more than usual.
- 1 I am more critical of myself than I used to be.
- 2 I criticize myself for all of my faults.
- 3 I blame myself for everything bad that happens.

9. Suicidal Thoughts or Wishes
- 0 I don't have any thoughts of killing myself.
- 1 I have thoughts of killing myself, but I would not carry them out.
- 2 I would like to kill myself.
- 3 I would kill myself if I had the chance.

10. Crying
- 0 I don't cry anymore than I used to.
- 1 I cry more than I used to.
- 2 I cry over every little thing.
- 3 I feel like crying, but I can't.

_____ Subtotal Page 1

Continued on Back

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Appendix E (continued)

11. Agitation

0 I am no more restless or wound up than usual.
1 I feel more restless or wound up than usual.
2 I am so restless or agitated that it's hard to stay still.
3 I am so restless or agitated that I have to keep moving or doing something.

12. Loss of Interest

0 I have not lost interest in other people or activities.
1 I am less interested in other people or things than before.
2 I have lost most of my interest in other people or things.
3 It's hard to get interested in anything.

13. Indecisiveness

0 I make decisions about as well as ever.
1 I find it more difficult to make decisions than usual.
2 I have much greater difficulty in making decisions than I used to.
3 I have trouble making any decisions.

14. Worthlessness

0 I do not feel I am worthless.
1 I don't consider myself as worthwhile and useful as I used to.
2 I feel more worthless as compared to other people.
3 I feel utterly worthless.

15. Loss of Energy

0 I have as much energy as ever.
1 I have less energy than I used to have.
2 I don't have enough energy to do very much.
3 I don't have enough energy to do anything.

16. Changes in Sleeping Pattern

0 I have not experienced any change in my sleeping pattern.
1a I sleep somewhat more than usual.
1b I sleep somewhat less than usual.
2a I sleep a lot more than usual.
2b I sleep a lot less than usual.
3a I sleep most of the day.
3b I wake up 1–2 hours early and can't get back to sleep.

17. Irritability

0 I am no more irritable than usual.
1 I am more irritable than usual.
2 I am much more irritable than usual.
3 I am irritable all the time.

18. Changes in Appetite

0 I have not experienced any change in my appetite.
1a My appetite is somewhat less than usual.
1b My appetite is somewhat greater than usual.
2a My appetite is much less than before.
2b My appetite is much greater than usual.
3a I have no appetite at all.
3b I crave food all the time.

19. Concentration Difficulty

0 I can concentrate as well as ever.
1 I can't concentrate as well as usual.
2 It's hard to keep my mind on anything for very long.
3 I find I can't concentrate on anything.

20. Tiredness or Fatigue

0 I am no more tired or fatigued than usual.
1 I get more tired or fatigued more easily than usual.
2 I am too tired or fatigued to do a lot of the things I used to do.
3 I am too tired or fatigued to do most of the things I used to do.

21. Loss of Interest in Sex

0 I have not noticed any recent change in my interest in sex.
1 I am less interested in sex than I used to be.
2 I am much less interested in sex now.
3 I have lost interest in sex completely.

22 23 24 25 26 27 28 29 30 A B C D E

_____ Subtotal Page 2
_____ Subtotal Page 1
_____ Total Score

Appendix E (continued)

SELF-EVALUATION QUESTIONNAIRE

Developed by Charles D. Spielberger
in collaboration with
R. L. Gorsuch, R. Lushene, P. R. Vagg, and G. A. Jacobs

STAI Form Y-1

Name _____ Date _____ S ____

Age _____ Sex: M ____ F ____ T ____

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you feel *right* now, that is, *at this moment*. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe your present feelings best.

	NOT AT ALL	SOMEWHAT	MODERATELY SO	VERY MUCH SO
1. I feel calm	①	②	③	④
2. I feel secure	①	②	③	④
3. I am tense	①	②	③	④
4. I feel strained	①	②	③	④
5. I feel at ease	①	②	③	④
6. I feel upset	①	②	③	④
7. I am presently worrying over possible misfortunes	①	②	③	④
8. I feel satisfied	①	②	③	④
9. I feel frightened	①	②	③	④
10. I feel comfortable	①	②	③	④
11. I feel self-confident	①	②	③	④
12. I feel nervous	①	②	③	④
13. I am jittery	①	②	③	④
14. I feel indecisive	①	②	③	④
15. I am relaxed	①	②	③	④
16. I feel content	①	②	③	④
17. I am worried	①	②	③	④
18. I feel confused	①	②	③	④
19. I feel steady	①	②	③	④
20. I feel pleasant	①	②	③	④

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Appendix E (continued)

SELF-EVALUATION QUESTIONNAIRE

STAI Form Y-2

Name _____ Date _____

DIRECTIONS: A number of statements which people have used to describe themselves are given below. Read each statement and then blacken in the appropriate circle to the right of the statement to indicate how you *generally* feel. There are no right or wrong answers. Do not spend too much time on any one statement but give the answer which seems to describe how you generally feel.

	ALMOST NEVER	SOMETIMES	OFTEN	ALMOST ALWAYS
21. I feel pleasant	①	②	③	④
22. I feel nervous and restless	①	②	③	④
23. I feel satisfied with myself	①	②	③	④
24. I wish I could be as happy as others seem to be	①	②	③	④
25. I feel like a failure	①	②	③	④
26. I feel rested	①	②	③	④
27. I am "calm, cool, and collected"	①	②	③	④
28. I feel that difficulties are piling up so that I cannot overcome them	①	②	③	④
29. I worry too much over something that really doesn't matter	①	②	③	④
30. I am happy	①	②	③	④
31. I have disturbing thoughts	①	②	③	④
32. I lack self-confidence	①	②	③	④
33. I feel secure	①	②	③	④
34. I make decisions easily	①	②	③	④
35. I feel inadequate	①	②	③	④
36. I am content	①	②	③	④
37. Some unimportant thought runs through my mind and bothers me	①	②	③	④
38. I take disappointments so keenly that I can't put them out of my mind	①	②	③	④
39. I am a steady person	①	②	③	④
40. I get in a state of tension or turmoil as I think over my recent concerns and interests	①	②	③	④

Appendix E (continued)

Q2

STAXI: DESCRIBE SELF

	Circle the number that indicates how you feel **right now.**	Not at all	Somewhat	Moderately so	Very much so
1	I am furious.	1	2	3	4
2	I feel irritated.	1	2	3	4
3	I feel angry.	1	2	3	4
4	I feel like yelling at someone.	1	2	3	4
5	I feel like breaking things.	1	2	3	4
6	I am mad.	1	2	3	4
7	I feel like banging on the table.	1	2	3	4
8	I feel like hitting someone.	1	2	3	4
9	I am burned up.	1	2	3	4
10	I feel like swearing.	1	2	3	4

	Circle the number that indicates how you **generally feel.**	Not at all	Somewhat	Moderately so	Very much so
1	I am quick tempered.	1	2	3	4
2	I have a fiery temper.	1	2	3	4
3	I am a hotheaded person.	1	2	3	4
4	I get angry when I'm slowed down by others mistakes.	1	2	3	4
5	I feel annoyed when I am not given recognition for doing good work.	1	2	3	4
6	I fly off the handle.	1	2	3	4
7	When I get mad, I say nasty things.	1	2	3	4
8	It makes me furious when I am criticized in front of others.	1	2	3	4
9	When I get frustrated, I feel like hitting someone.	1	2	3	4
10	I feel infuriated when I do a good job and get a poor evaluation.	1	2	3	4

Appendix E (continued)

Q2

	ENRICHD SS: INTERACTION WITH OTHERS How much of the time…	None of the time	A little of the time	Some of the time	Most of the time	All of the time
1	Is there someone available to you, whom you can count on to listen to you when you need to talk?	1	2	3	4	5
2	Is there someone available to you to give you good advice about a problem?	1	2	3	4	5
3	Is there someone available to you who shows you love and affection?	1	2	3	4	5
4	Is there someone available to help with daily chores?	1	2	3	4	5
5	Can you count on anyone to provide you with emotional support (talking over problems or helping you make a difficult decision)?	1	2	3	4	5
6	Do you have as much contact as you would like with someone you feel close to, someone in whom you can trust and confide in?	1	2	3	4	5
7	Are you currently married or living with a partner?	No	Yes			
8	Do you have any children?	No	Yes			

	ODCIF: INTERACTION WITH FAMILY Indicate how much you agree or disagree with each statement.	Strongly agree	Agree	Disagree	Strongly disagree
1	I talk as little as possible about my illness because I don't want to make my family uneasy.	1	2	3	4
2	My partner doesn't like me to talk about my problems. (If not applicable, check here ____).	1	2	3	4
3	My children don't like me to talk about my problems. (If not applicable, check here ____).	1	2	3	4
4	If I talk about my illness, others gloss over it.	1	2	3	4
5	My family always wants to hear from me that I am doing well.	1	2	3	4
6	Talking about emotions related to my illness upsets my family.	1	2	3	4
7	My partner often doesn't know what to say or to do when I'm feeling down. (If not applicable, check here ____).	1	2	3	4
8	My children often don't know what to say or to do when I'm feeling down. (If not applicable, check here ____).	1	2	3	4

Appendix E (continued)

Q2

	EXERCISE: During the past week, even if it was not a typical week for you, how much **total** time (for the **entire week**) did you spend on each of the following? (Please circle one number for each question.)	None	Less than 30 min/wk	30-60 min/wk	1-3 hours/wk	More than 3 hours/wk
1	Stretching or strengthening exercises (range of motion, using weights, etc.)	0	1	2	3	4
2	Walk for exercise	0	1	2	3	4
3	Swimming or aquatic exercise	0	1	2	3	4
4	Bicycling (including stationary exercise bikes)	0	1	2	3	4
5	Other aerobic exercise equipment (Stairmaster, rowing, skiing machine, etc.)	0	1	2	3	4
6	Other aerobic exercise Specify _____	0	1	2	3	4

	CDC: TOBACCO								
1	Have you ever smoked or consumed any kind of tobacco every day for at least 30 days?	Yes	No- Skip to question #8 on this page						
2	What kind of tobacco did you use for at least 30 days (circle all that apply)	Cigarette	Chew	Snuff	Cigar	Pipe			
3	How old were you when you first started consuming tobacco everyday?	____ years							
4	When you consumed tobacco, how many (cigarettes or times) did you (smoke/dip/chew) per day?	____ per day							
5	How long has it been since you last consumed tobacco?	____ days	____ months	____ years	If more than 30 days, skip to #8 on this page				
6	How many days out of the past 30 days did you consume tobacco?	____/ 30 days							
7	How many (cigarettes/ times) did you (smoke/chew/dip) per day, on average in the past 30 days?	____							
8	During the past 7 days, how many days were you in the same room with someone who was smoking cigarettes?	0	1	2	3	4	5	6	7

Appendix E (continued)

AUDIT: ALCOHOL							
1	How often do you have a drink containing alcohol?	Never	Monthly or less	2 to 4 times a month	2 to 3 times a week	4 or more times a week	
2	How many drinks containing alcohol do you have on a typical day when you are drinking?	1 or 2	3 or 4	5 or 6	7 to 9	10 or more	
3	How often do you have six or more drinks on one occasion?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily	
4	How often during the last year have you found that you were not able to stop drinking once you had started?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily	
5	How often during the last year have you failed to do what was normally expected from you because of drinking?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily	
6	How often during the last year have you needed a first drink in the morning to get yourself going after a heavy drinking session?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily	
7	How often during the last year have you had a feeling of guilt or remorse after drinking?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily	
8	How often during the last year have you been unable to remember what happened the night before because you had been drinking?	Never	Less than monthly	Monthly	Weekly	Daily or almost daily	
9	Have you or someone else been injured as a result of your drinking?	No		Yes, but not in the last year		Yes, during the last year	
10	Has a relative or friend, or a doctor or other health worker been concerned about your drinking or suggested you cut down?	No		Yes, but not in the last year		Yes, during the last year	

Q2

Appendix E (continued)

MOS: HEALTH RECOMMENDATIONS: Place a **check mark** after the recommendations that have been made by your doctor, nurse, or other health care professionals in regard to your health **now**.	√
1 Follow a low salt diet?	
2 Follow a low fat or weight loss diet?	
3 Follow a diabetic diet?	
4 Follow a renal diet?	
5 Take a prescribed medication?	
6 Check your blood sugar?	
7 Take part in a cardiac rehabilitation program?	
8 Exercise regularly?	
9 Socialize more than usual with others?	
10 Cut down on the alcohol you drink?	
11 Stop or cut down on smoking?	
12 Check your feet for minor bruises, injuries, and ingrown toenails?	
13 Cut down on stress in your life?	
14 Use relaxation techniques like biofeedback or self-hypnosis?	
15 Carry something with sugar in it as a source of glucose for emergencies?	
16 Carry medical supplies needed for your self-care?	

MOS: HEALTH RECOMMENDATIONS	None of the time	A little of the time	Some of the time	A good bit of the time	Most of the time	All of the time
5 Generally speaking, how often during the past 4 weeks were you able to do what the doctor told you?	1	2	3	4	5	6

Q2

Appendix E (continued)

Q2

	IES: ILLNESS: Below is a list of comments made by people after stressful life events, like being diagnosed with a serious illness. For each statement, please indicate how frequently these comments were true for you during the **past week** in regard to **your illness**.	Not at all	Rarely	Sometimes	Often
1	I thought about it when I didn't mean to.	0	1	2	3
2	I avoided letting myself get upset when I thought about it or was reminded of it.	0	1	2	3
3	I tried to remove it from memory.	0	1	2	3
4	I had trouble falling asleep or staying asleep, because of pictures or thoughts about it that came into my mind.	0	1	2	3
5	I had waves of strong feelings about it.	0	1	2	3
6	I had dreams about it.	0	1	2	3
7	I stayed away from reminders of it.	0	1	2	3
8	I felt as if it hadn't happened or it wasn't real.	0	1	2	3
9	I tried not to talk about it.	0	1	2	3
10	Pictures about it popped into my mind.	0	1	2	3
11	Other things kept making me think about it.	0	1	2	3
12	I was aware that I still had a lot of feelings about it, but I didn't deal with them.	0	1	2	3
13	I tried not to think about it.	0	1	2	3
14	Any reminder brought back feelings about it.	0	1	2	3
15	My feelings about it were kind of numb.	0	1	2	3

Please list any **comments** about this questionnaire (Examples: What was the hardest part of filling it out? Was there a question you didn't like?).

_____

_____

_____

_____

_____

_____

_____

_____

Appendix F

Global Assessment of Functioning (GAF) Scale

(From DSM-IV-TR, p. 34.)

Consider psychological, social, and occupational functioning on a hypothetical continuum of mental health-illness. Do not include impairment in functioning due to physical (or environmental) limitations.

Code	(Note: Use intermediate codes when appropriate, e.g., 45, 68, 72.)
100 | 91	**Superior functioning in a wide range of activities, life's problems never seem to get out of hand, is sought out by others because of his or her many positive qualities. No symptoms.**
90 | 81	**Absent or minimal symptoms** (e.g., mild anxiety before an exam**), good functioning in all areas, interested and involved in a wide range of activities. socially effective, generally satisfied with life, no more than everyday problems or concerns** (e.g. an occasional argument with family members).
80 | 71	**If symptoms are present, they are transient and expectable reactions to psychosocial stressors** (e.g., difficulty concentrating after family argument); **no more than slight impairment in social, occupational or school functioning** (e.g., temporarily failing behind in schoolwork).
70 | 61	**Some mild symptoms** (e.g. depressed mood and mild insomnia) **OR some difficulty in social, occupational, or school functioning** (e.g., occasional truancy, or theft within the household)**, but generally functioning pretty well, has some meaningful interpersonal relationships.**
60 | 51	**Moderate symptoms** (e.g., flat affect and circumstantial speech, occasional panic attacks) **OR moderate difficulty in social, occupational, or school functioning** (e.g.. few friends, conflicts with peers or co-workers).
50 | 41	**Serious symptoms** (e.g.. suicidal ideation, severe obsessional rituals, frequent shoplifting) **OR any serious impairment in social, occupational, or school functioning** (e.g., no friends, unable to keep a job).
40 | 31	**Some impairment in reality testing or communication** (e.g., speech is at times illogical, obscure, or irrelevant) **OR major impairment in several areas, such as work or school, family relations, judgment, thinking, or mood** (e.g., depressed man avoids friends, neglects family, and is unable to work; child frequently beats up younger children, is defiant at home, and is failing at school).
30 | 21	**Behavior is considerably influenced by delusions or hallucinations** **OR serious impairment in communication or judgment** (e.g., sometimes incoherent, acts grossly inappropriately, suicidal preoccupation) **OR inability to function in almost all areas** (e.g., stays in bed all day; no job, home, or friends).
20 | 11	**Some danger of hurting self or others** (e.g., suicide attempts without clear expectation of death; frequently violent; manic excitement) **OR occasionally fails to maintain minimal personal hygiene** (e.g., smears feces) **OR gross impairment in communication** (e.g., largely incoherent or mute).
10 | 1	**Persistent danger of severely hurting self or others** (e.g., recurrent violence) **OR persistent inability to maintain minimal personal hygiene** **OR serious suicidal act with clear expectation of death.**
0	Inadequate information.

Appendix G

MAYO CLINIC

Name and Clinic Number

IRB # **08-006915 00**
Consent form approved **December 8, 2011**;
This consent valid through **December 7, 2012**;

1. General Information About This Research Study

Study Title: The role of health behaviors in hematopoietic stem cell transplantation

Name of Principal Investigator on this Study: Dr. Shawna. L. Ehlers and Colleagues

A. Study Eligibility and Purpose

You are being asked to take part in this research study because you are undergoing a stem cell / bone marrow transplant. We are examining the impact of health behaviors on transplant patient health. This information will be used to develop guidelines and treatments to improve current patient care.

Your health care provider may be referring you to this study and may be an investigator in this study. While he or she is referring you to this study because of your potential interest, by being an investigator in this study, she or he has a conflict having two sets of priorities (your well-being and the scientific conduct of the study).

As you read this form describing the study, ask any questions you have. Take your time to decide. Feel free to discuss the study with your family, friends, and healthcare provider before you decide. If you decide to participate, you may stop participating at any time during the study. You may decide not to participate. If so, none of your current benefits or normal health care will be affected in any way. When you feel comfortable that all your questions have been answered, and you wish to take part in this study, sign this form in order to begin your participation. If you are agreeing for someone else, you need to sign this form. Your signature means you have been told about the study and what the risks are. Your signature on this form also means that you want yourself, or your child/relative/principal/ward to take part in this study.

B. Number of Participants

The plan is to have 1,000 people take part in this study at Mayo Clinic.

Appendix G (continued)

MAYO CLINIC

C. Additional Information You Should Know

The National Institute of Health (NIH) is funding the study. NIH will pay your study doctor or the institution to cover costs related to running the study.

2. What Will Happen To You While You Are In This Research Study?

If you agree to be in the study, you will be asked to participate in the following:

1) Before your transplant, you will be asked to fill out a brief questionnaire on health behaviors such as exercise, alcohol, and tobacco use that will take approximately 15 minutes to answer.

2) After your transplant, you will be asked to complete a second questionnaire with similar questions that will take approximately 15 minutes to answer.

3) Information from your medical record will be used for this research study.

3. How Long Will You Be in This Research Study?

You will be in the study for as long as you are followed by Mayo Clinic as a transplant patient.

4. Why You Might Want To Take Part In This Research Study

This study will not make your health better. It is for the benefit of research. What we learn from this study may result in better patient care in the future, including best advice to transplant patients on what they can do to protect their health and promote highest quality of life.

Appendix G (continued)

MAYO CLINIC

5. What Are the Risks Of This Research Study?

Some questions you will be asked to answer in the study questionnaire(s) may make you feel uncomfortable. You may choose not to answer any questions that make you feel uncomfortable.

Risk summary

The risks of this research study are minimal, which means that we do not believe that they will be any different than what you would experience at a routine clinical visit or during your daily life.

6. What Other Choices Do You Have If You Don't Take Part In This Research Study?

This study is only being done to gather information. You may choose not to take part in this study.

7. Are There Reasons You Might Leave This Research Study Early?

Taking part in this research study is voluntary. You may decide to stop at any time. You should tell the researcher if you decide to stop and you will be advised whether any additional tests may need to be done for your safety.

In addition, the researchers, NIH, or Mayo may stop you from taking part in this study at any time:

- if it is in your best clinical interest,
- if you do not follow the study procedures,
- if the study is stopped.

Appendix G (continued)

MAYO CLINIC

8. Will You Need To Pay For Any Of The Tests And Procedures?

You will not need to pay for tests and procedures which are done just for this research study.

However, you and/or your health plan will need to pay for all other tests and procedures that you would normally have as part of your regular clinical care.

If you have study related questions regarding billing, insurance or reimbursement, stop by or call:

Rochester: Admission and Business Services office, or call Patient Account Services at (507) 266-5670

9. Will You Be Paid For Participating In This Research Study?

You will not be paid for taking part in this study.

10. What Happens If You Are Injured Or Ill Because You Were In This Research Study?

If you have side effects from taking part in this study, you need to report them to the researcher and your regular physician, and you will be treated as needed. Mayo will give medical services for treatment for any bad side effects from taking part in this study. Such services will be free if not covered by a health plan or insurance. No additional money will be offered.

Appendix G (continued)

MAYO CLINIC

11. What Are Your Rights If You Are In This Research Study?

Taking part in this research study will not change your rights and benefits. Taking part in this research study does not give you any special privileges. If you decide to not participate in this study, or stop in the middle of the study, no benefits are taken away from you. Specifically, you do not have to be in this research study to receive or continue to receive medical care from Mayo Clinic.

You will be told of important new findings or any changes in the study or procedures that may affect you or your willingness to continue in the study.

12. What About Your Privacy?

Authorization To Use And Disclose Protected Health Information

Your privacy is important to us, and we want to protect it as much as possible. By signing this form, you authorize Mayo Clinic and the investigators to use and disclose any information created or collected in the course of your participation in this research protocol. This information might be in different places, including your original medical record, but we will only disclose information that is related to this research protocol for the purposes listed below.

This information will be given out for the proper monitoring of the study, checking the accuracy of study data, analyzing the study data, and other purposes necessary for the proper conduct and reporting of this study. If some of the information is reported in published medical journals or scientific discussions, it will be done in a way that does not directly identify you.

This information may be given to other researchers in this study, or private, state or federal government parties or regulatory authorities in the USA and other countries responsible for overseeing this research. These may include the Food and Drug Administration, the Office for Human Research Protections, or other offices within the Department of Health and Human Services, and the Mayo Clinic Office for Human Research Protections or other Mayo groups involved in protecting research subjects.

This authorization lasts until the end of the study. The study does not end until all data has been collected, checked (or audited) and analyzed. Sometimes this can be years after your study visits have ended. For example, this could happen if the results of the study are filed with a regulatory agency like the Food and Drug Administration.

Appendix G (continued)

MAYO CLINIC

You may stop this authorization at any time by writing to the following address:

Mayo Clinic
Office for Human Research Protection
ATTN: Notice of Revocation of Authorization
200 1st Street SW
Rochester, MN 55905

If you stop authorization, Mayo may continue to use your information already collected as part of this study, but will not collect any new information.

13. What Will Happen to Your Samples?

No biological samples will be collected as part of this research study.

14. Who Can Answer Your Questions?

You can call …	At …	If you have questions or concerns about …
Principal Investigator: Shawna Ehlers, PhD, LP	**Phone 507-284-4431**	**Questions about the study tests and procedures**
		Research-related injuries or emergencies
Study Coordinator: Chris Hughes	**Phone 507-538-7443**	**Any research-related concerns or complaints**
Mayo Clinic IRB	**Phone: 507-266-4000**	**Rights of a research subject**
Research Subject Advocate:	**Toll-Free: 866-273-4681**	**Use of Protected Health Information**
		Any research-related concerns or complaints
Research Billing	**Rochester: 507-266-5670**	**Billing / Insurance Questions**

Appendix G (continued)

15. Summary and Enrollment Signatures

You have been asked to take part in a research study, at Mayo Clinic. The information about this study has been provided to you to inform you about this study.

- I have read the whole consent form, and all of my questions have been answered to my satisfaction.
- I am satisfied that I have been given enough information about the purpose, methods, risks, and possible benefits of the study to decide if I want to join.
- I know that joining the study is voluntary and I agree to join the study.
- I know that I can call the investigator and research staff at any time with any questions or to tell them about side effects.
- I know that I may withdraw from the study at any time.
- I will be given a copy of this completed form.

Please sign and date to show that you have read all of the above guidelines. Please do not sign unless you have read this entire consent form. If you do not want to sign, you don't have to, but if you don't you cannot participate in this research study.

_____	_____	_____
(Date / Time)	(Printed Name of Participant)	(Clinic Number)

_____
(Signature of Participant)

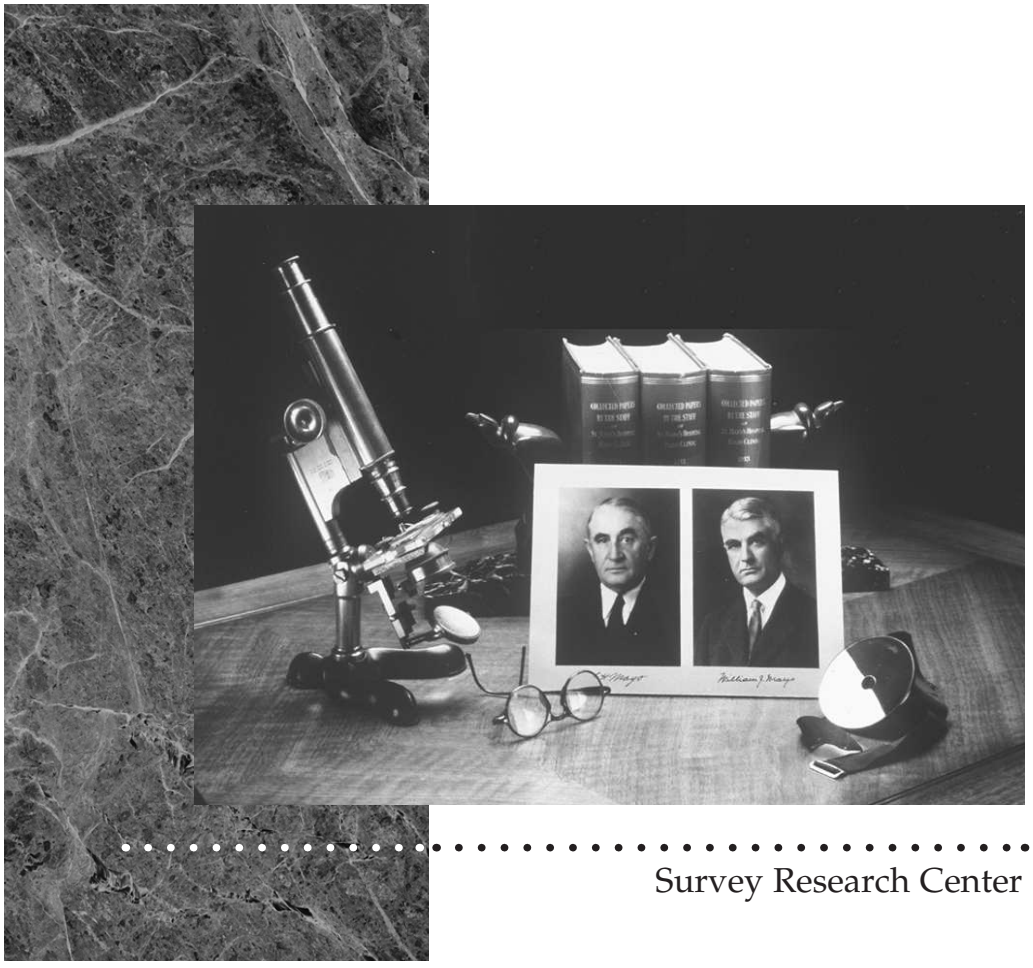
_____	_____
(Date / Time)	(Printed Name of Individual Obtaining Consent)

_____
(Signature of Individual Obtaining Consent)

Appendix H

MAYO CLINIC

Lifestyle Survey for Transplant Patients (Pre-Transplant)



Survey Research Center

Appendix H (continued)

Name: _____
First/Middle Initial/Last

Mayo Clinic Number: ___-___ ___ ___-___ ___ ___

INSTRUCTIONS: PLEASE CHECK THE APPROPRIATE BOX OR FILL IN THE BLANK AS INDICATED.

1. **Today's Date:** __ __/__ __/__ __ __ __
Month Day Year

2. **What is your height?** ___ Feet ___ ___ Inches (Round to the nearest inch.)

3. **What is your weight?** ___ ___ ___ Pounds (Round to the nearest pound.)

4. **What is your highest lifetime weight?**

___ ___ ___ Pounds (Do not include pregnancy weight, and round to the nearest pound.)

5. **In the past 12 months, did any doctor, nurse, or other health professional ADVISE you to...** (Check one box per line.)

	Yes	No
exercise more?	1 ☐	2 ☐
eat better?	1 ☐	2 ☐
lose weight?	1 ☐	2 ☐
reduce alcohol use?	1 ☐	2 ☐
quit tobacco?	1 ☐	2 ☐

In the past 12 months, did any <u>doctor, nurse, or other health professional</u>... (Check one box per line.)	Yes	No
<u>prescribe</u> a nicotine patch, spray, inhaler, lozenge, or pill (Zyban, Chantix) to help you quit tobacco?	1 ☐	2 ☐
provide you with booklets, videos, or other <u>materials</u> to help you quit tobacco on your own?	1 ☐	2 ☐
<u>suggest</u> that you use a tobacco cessation class, program, quit line, or counseling?	1 ☐	2 ☐

Appendix H (continued)

6. When would be the <u>best</u> time to help transplant patients... (Check one box per line.)

	Time of diagnosis	When patient decides to have transplant	After recovery from transplant	Other time, please specify
exercise more?	1 ☐	2 ☐	3 ☐	4 ☐ _____
eat better?	1 ☐	2 ☐	3 ☐	4 ☐ _____
lose weight?	1 ☐	2 ☐	3 ☐	4 ☐ _____
reduce alcohol use?	1 ☐	2 ☐	3 ☐	4 ☐ _____
quit tobacco?	1 ☐	2 ☐	3 ☐	4 ☐ _____

7. Who is your primary transplant caregiver? (Check one box.)

1 ☐ Spouse/partner 2 ☐ Friend 3 ☐ Child 4 ☐ Other, please specify: _____

8. How would your primary transplant caregiver react to you... (Check one box per line.)

	1 Strongly encouraging	2	3	4	5 Strongly discouraging
exercising more?	☐	☐	☐	☐	☐
eating better?	☐	☐	☐	☐	☐
losing weight?	☐	☐	☐	☐	☐
reducing alcohol use?	☐	☐	☐	☐	☐
0 ☐ I do not drink					
quitting tobacco?	☐	☐	☐	☐	☐
0 ☐ I do not use tobacco					

9. Since your transplant-related diagnosis, has your... (Check one box per line.)

	Increased	Decreased	Stayed the same
exercise	1 ☐	2 ☐	3 ☐
healthy food intake (e.g., fruits, vegetables, etc.)	1 ☐	2 ☐	3 ☐
weight	1 ☐	2 ☐	3 ☐
alcohol <u>use</u> 0 ☐ I do not drink	1 ☐	2 ☐	3 ☐
tobacco <u>use</u> 0 ☐ I do not use tobacco	1 ☐	2 ☐	3 ☐

Appendix H (continued)

10. How important do you think the following health behaviors are to your health? (Check one box per line.)

	Not at all	A little important	Somewhat important	Very important
Exercise	1 ☐	2 ☐	3 ☐	4 ☐
Nutrition	1 ☐	2 ☐	3 ☐	4 ☐
Weight	1 ☐	2 ☐	3 ☐	4 ☐
Alcohol use? 0 ☐ I do not drink	1 ☐	2 ☐	3 ☐	4 ☐
Tobacco use? 0 ☐ I do not use tobacco	1 ☐	2 ☐	3 ☐	4 ☐

11. During the past 7 days, on <u>how many days</u> were you in the <u>same room</u> with someone who was smoking cigarettes? (Check the best answer.)

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

12. During the past 7 days, on <u>how many days</u> were you in a <u>car</u> with someone who was smoking cigarettes? (Check the best answer.)

☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

13. Please choose "True" or "False" for each statement below. (Check one box per line.)

	True	False
I currently do not exercise	1 ☐	2 ☐
I intend to exercise in the next 6 months	1 ☐	2 ☐
I currently exercise *regularly*	1 ☐	2 ☐
I have exercised *regularly* **for the past 6 months**	1 ☐	2 ☐
I exercised *regularly* **before my transplant-related diagnosis**	1 ☐	2 ☐
I intend to exercise more after transplant	1 ☐	2 ☐

Skip to question 14 on page 4.

Why do you want to exercise more? (Check all that apply.)

1 ☐ Improve health
1 ☐ Relieve illness symptoms
1 ☐ Set example for children
1 ☐ My family/friends want me to
1 ☐ My doctor wants me to
1 ☐ Other, specify: _____

What would make it difficult to exercise more? (Check all that apply.)

1 ☐ Stress/mood
1 ☐ Fatigue
1 ☐ No time
1 ☐ Enjoy life as it is now
1 ☐ Pressure from family/friends to not change
1 ☐ Other, specify: _____

On a scale of 1 to 10, with 1 being "Not at all confident" and 10 being "Completely confident," how confident are you in your ability to exercise more? (Check one.)

1	2	3	4	5	6	7	8	9	10
Not at all confident									Completely confident

Appendix H (continued)

14. During the past week, even if it was not a typical week for you, how much total time (for the entire week) did you spend on each of the following? (Check one box per line.)

	None	Less than 30 minutes	30 to 59 minutes	1 to 3 hours	More than 3 hours
Stretching or strengthening exercises (range of motion, using weights, etc.)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Walking for exercise	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Swimming for aquatic exercise	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Bicycling (including stationary exercise bikes)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Other aerobic exercise equipment (stairmaster, rowing, skiing machine, etc.)	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
Other aerobic exercise, specify: _____	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐

15. How many servings of fruit do you usually eat each day? (Check the best answer.)

0 ☐ 0 1 ☐ 1 2 ☐ 2 3 ☐ 3 to 4 4 ☐ 5 to 6 5 ☐ 7 or more

16. How many servings of vegetables do you usually eat each day? (Check the best answer.)

0 ☐ 0 1 ☐ 1 2 ☐ 2 3 ☐ 3 to 4 4 ☐ 5 to 6 5 ☐ 7 or more

17. I intend to improve my nutrition after transplant.

1 ☐ True 2 ☐ False → **Skip to question 18 on page 5.**

Why do you want to improve your nutrition? (Check all that apply.)

1 ☐ Improve health
1 ☐ Relieve illness symptoms
1 ☐ Set example for children
1 ☐ My family/friends want me to
1 ☐ My doctor wants me to
1 ☐ Other, specify: _____

What would make it difficult to improve your nutrition? (Check all that apply.)

1 ☐ Stress/mood
1 ☐ Fatigue
1 ☐ No time
1 ☐ Enjoy life as it is now
1 ☐ Pressure from family/friends to not change
1 ☐ Other, specify: _____

On a scale of 1 to 10, with 1 being "Not at all confident" and 10 being "Completely confident," how confident are you in your ability to improve your nutrition? (Check one.)

1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10 ☐

Not at all confident — Completely confident

Appendix H (continued)

18. When is the last time you used any type of tobacco (even 1 or 2 puffs, chew, etc.)?

1 ☐ 0 to 7 days ago
2 ☐ 8 days to 6 months ago
3 ☐ 6 to 12 months ago
4 ☐ More than 12 months ago
5 ☐ Never → **Skip to question 28 on page 7.**

19. I intend to to be tobacco free (quit or remain quit).

1 ☐ True
2 ☐ False → **Skip to question 20 below.**

Why do you want to be tobacco free? (Check all that apply.)

1 ☐ Improve health
1 ☐ Relieve illness symptoms
1 ☐ Set example for children
1 ☐ My family/friends want me to
1 ☐ My doctor wants me to
1 ☐ Other, specify: _____

What makes it difficult to be tobacco free? (Check all that apply.)

1 ☐ Stress/mood
1 ☐ Fatigue
1 ☐ No time
1 ☐ Enjoy life as it is now
1 ☐ Pressure from family/friends to not change
1 ☐ Other, specify: _____

20. In your life, how many years have you used tobacco altogether?

___ ___ Years

21. What kind of tobacco did/do you use? (Mark all that apply.)

1 ☐ Cigarette
1 ☐ Chew/snuff
1 ☐ Cigar/pipe
1 ☐ Other

Have you smoked 100 cigarettes in your entire life?

1 ☐ Yes
2 ☐ No

How many <u>cigarettes</u> did you smoke <u>per day</u>, on average in... (Check one box per line.)	0	10 or less	11 to 20	21 to 30	31 or more
the past 7 days	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
the past 6 months	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
the past 12 months	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
more than 12 months ago	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

Appendix H (continued)

22. Have you quit using tobacco?

1 ☐ Yes → **If yes, when did you stop?** __ __/__ __/__ __ __ __ (Month Day Year)

2 ☐ No

Skip to question 28 on page 7.

23. How soon after you wake up do you have your first cigarette/tobacco?

1 ☐ 0 to 5 minutes 2 ☐ 6 to 30 minutes 3 ☐ 31 to 60 minutes 4 ☐ More than 60 minutes

24. Do you find it difficult to refrain from tobacco in places where it is forbidden, e.g., in a church, on an airplane, at the movies, etc.?

1 ☐ Yes 2 ☐ No

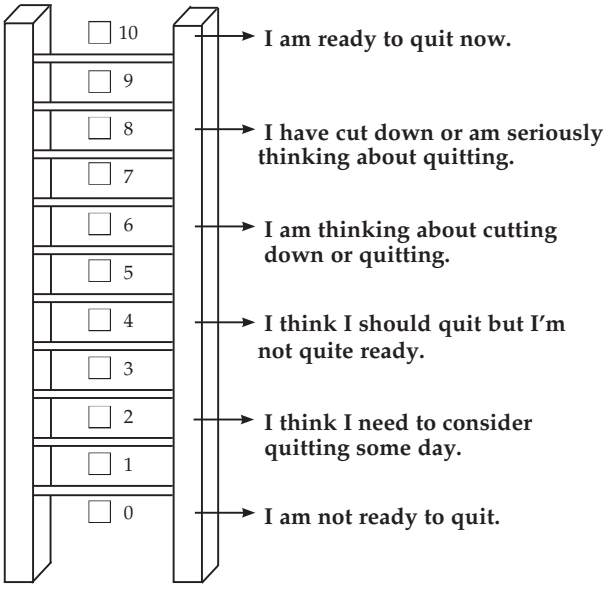
25. Do you smoke/use tobacco if you are so ill that you are in bed most of the day?

1 ☐ Yes 2 ☐ No

26. Readiness to Quit Tobacco

Each rung on this ladder represents where various tobacco-users are in their thinking about quitting.

Mark the box next to the number that indicates where you are now.



Appendix H (continued)

27. On a scale from 1 to 10, with 1 being "Not at all confident" and 10 being "Completely confident," how confident are you in your ability to quit tobacco? (Check one.)

☐1 ☐2 ☐3 ☐4 ☐5 ☐6 ☐7 ☐8 ☐9 ☐10

Not at all confident — Completely confident

28. In the past year, how often do you have a drink containing alcohol? (Check the answer that is correct for you.)

1 ☐ Never → **Skip to question 34 on page 8.**

2 ☐ Monthly or less

3 ☐ 2 to 4 times a month

4 ☐ 2 to 3 times a week

5 ☐ 4 or more times a week

29. How many drinks containing alcohol do you have on a typical day when you are drinking?

1 ☐ 1 or 2 2 ☐ 3 or 4 3 ☐ 5 or 6 4 ☐ 7 to 9 5 ☐ 10 or more

30. How often... (Check one box per line.)

	Never	Less than monthly	Monthly	Weekly	Daily or almost daily
do you have six or more drinks on one occasion?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
during the last year have you found that you were not able to stop drinking once you had started?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
during the last year have you failed to do what was normally expected from you because of drinking?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
during the last year have you needed a first drink in the morning to get yourself going after a heavy drinking session?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
during the last year have you had a feeling of guilt or remorse after drinking?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
during the last year have you been unable to remember what happened the night before because you had been drinking?	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐

31. Have you or someone else been injured as a result of your drinking?

1 ☐ No 2 ☐ Yes, but not in the last year 3 ☐ Yes, during the last year

Appendix H (continued)

32. Has a relative or friend, or a doctor or other health worker been <u>concerned</u> about your drinking or suggested you cut down?

1 ☐ No 2 ☐ Yes, but not in the last year 3 ☐ Yes, during the last year

33. Do you want to cut down on your drinking?

1 ☐ No 2 ☐ I have already 3 ☐ Yes

Why do you want to cut down (or remain cut down)?
(Check all that apply.)

1 ☐ Improve health
1 ☐ Relieve illness symptoms
1 ☐ Set example for children
1 ☐ My family/friends want me to
1 ☐ My doctor wants me to
1 ☐ Other, specify: _____

What would make it difficult to cut down (or remain cut down)?
(Check all that apply.)

1 ☐ Stress/mood
1 ☐ Fatigue
1 ☐ No time
1 ☐ Enjoy life as it is now
1 ☐ Pressure from family/friends to not change
1 ☐ Other, specify: _____

On a scale of 1 to 10, with 1 being "Not at all confident" and 10 being "Completely confident," how confident are you in your ability to cut down (or remain cut down)? (Check one.)

1	2	3	4	5	6	7	8	9	10
Not at all confident									Completely confident

34. Comments: _____

_____

_____

_____

_____

_____

_____

_____

Thank you for taking the time to complete the survey!

Appendix H (continued)

Appendix H (continued)

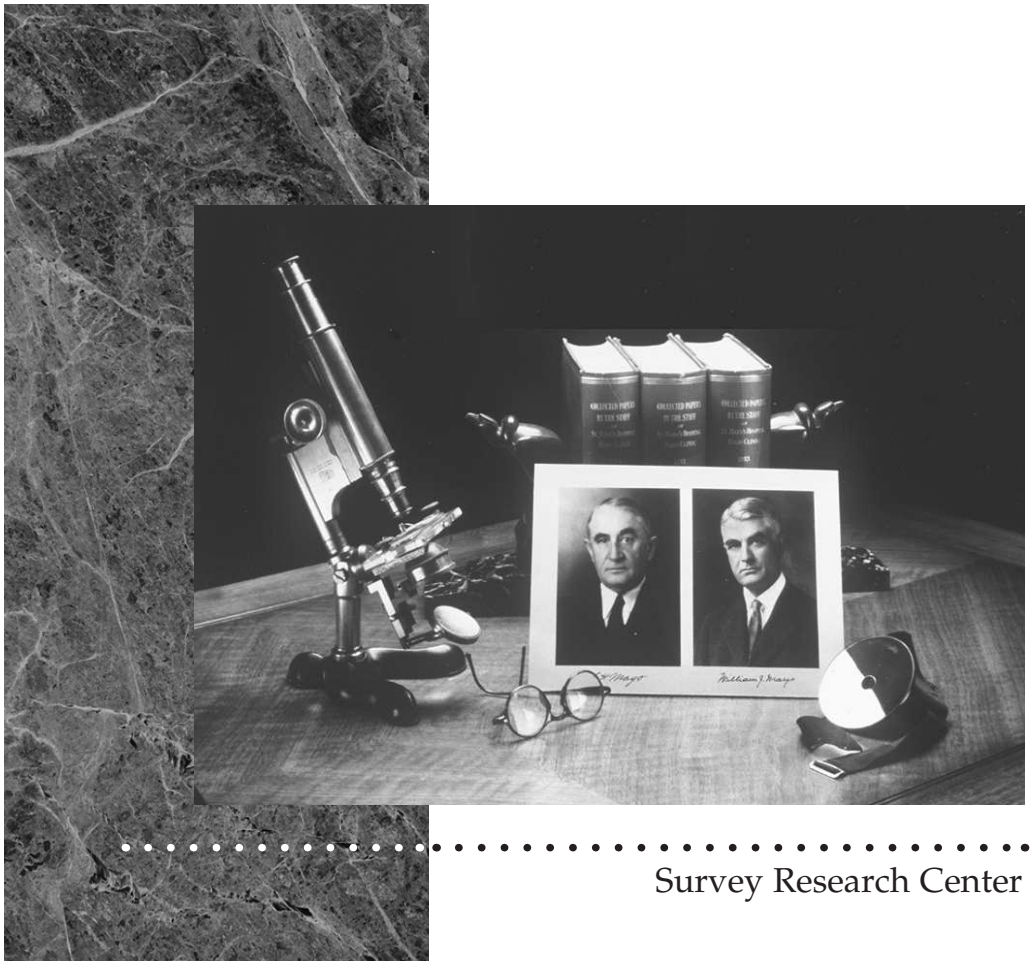
200 First Street SW
Rochester, Minnesota 55905
www.mayoclinic.org

MC4269-##

Appendix I

MAYO CLINIC

Lifestyle Survey for Transplant Patients (1-Year Follow-Up)



Survey Research Center

Appendix I (continued)

1-7

Clinic Number
Name
Address
Phone Number

Please enter above any missing information or change any that is incorrect.

INSTRUCTIONS: PLEASE CHECK THE APPROPRIATE BOX OR FILL IN THE BLANK AS INDICATED.

8-15 **1. Today's Date:** __ __/__ __/__ __ __ __
Month Day Year

16-18 **2. What is your weight?** ___ ___ ___ Pounds (Round to the nearest pound.)

3. Since your transplant, how many times have you been admitted to a hospital for <u>at least</u> one night?

19-20 ___ ___ Number of times admitted to a hospital

4. What best describes your transplant-related illness now? (Check all that apply.)

21:24 1☐ Remission/no disease
22:25 1☐ Improved, but disease is not completely gone
23:26 1☐ Disease is same or worse
1☐ No more treatment planned
1☐ More treatment planned
1☐ I am on treatment now

Instructions: We are interested in knowing about your symptoms. Check the **one** number from (0-10) best describing your feelings in the **PAST WEEK**, including today.

5. How would you describe:

Your level of fatigue, on average? (Check only one.)

No fatigue — Worst fatigue you can imagine

27-28 ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

Your degree of pain, on average? (Check only one.)

No pain — Worst pain you can imagine

29-30 ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

Your overall quality of life? (Check only one.)

As bad as it can be — As good as can be

31-32 ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

Appendix I (continued)

6. Would you say your current health is:

33 1 ☐ Excellent 2 ☐ Very good 3 ☐ Good 4 ☐ Fair 5 ☐ Poor

7. Since your transplant, did any doctor, nurse, or other health professional ADVISE you to... (Check one box per line.)

		Yes	No
34	**exercise more?**	1 ☐	2 ☐
35	**eat better?**	1 ☐	2 ☐
36	**lose weight?**	1 ☐	2 ☐
37	**gain weight?**	1 ☐	2 ☐
38:39	**reduce alcohol use?** 0 ☐ I do not drink	1 ☐	2 ☐
40:41	**quit tobacco?** 0 ☐ I do not use tobacco	1 ☐	2 ☐

8. When would be the <u>best</u> time to help transplant patients... (Check one box per line.)

		Time of diagnosis	When patient decides to have transplant	After recovery from transplant	Other time, please specify	
42	**exercise more?**	1 ☐	2 ☐	3 ☐	4 ☐	_____
43	**eat better?**	1 ☐	2 ☐	3 ☐	4 ☐	_____
44	**lose weight?**	1 ☐	2 ☐	3 ☐	4 ☐	_____
45	**gain weight?**	1 ☐	2 ☐	3 ☐	4 ☐	_____
46	**reduce alcohol use?**	1 ☐	2 ☐	3 ☐	4 ☐	_____
47	**quit tobacco?**	1 ☐	2 ☐	3 ☐	4 ☐	_____

9. How would your primary transplant caregiver react to you... (Check one box per line.)

48	**exercising more?**	☐ 1 Strongly encouraging	☐ 2	☐ 3	☐ 4	☐ 5 Strongly discouraging
49	**eating better?**	☐ 1 Strongly encouraging	☐ 2	☐ 3	☐ 4	☐ 5 Strongly discouraging
50	**losing weight?**	☐ 1 Strongly encouraging	☐ 2	☐ 3	☐ 4	☐ 5 Strongly discouraging

Continued next page...

Appendix I (continued)

51 **gaining weight?** . . . . . ☐ 1 Strongly encouraging ☐ 2 ☐ 3 ☐ 4 ☐ 5 Strongly discouraging

52 **reducing alcohol use?** . . . . . ☐ 1 Strongly encouraging ☐ 2 ☐ 3 ☐ 4 ☐ 5 Strongly discouraging

53 0 ☐ I do not drink

54 **quitting tobacco?** . . . . . ☐ 1 Strongly encouraging ☐ 2 ☐ 3 ☐ 4 ☐ 5 Strongly discouraging

55 0 ☐ I do not use tobacco

10. Since your transplant, has your...
(Check one box per line.)

		Increased	Decreased	Stayed the same
56	**exercise**	1 ☐	2 ☐	3 ☐
57	**healthy food intake (e.g., fruits, vegetables, etc.)**	1 ☐	2 ☐	3 ☐
58	**weight**	1 ☐	2 ☐	3 ☐
59:60	**alcohol use** . . . 0 ☐ I do not drink	1 ☐	2 ☐	3 ☐
61:62	**tobacco use** . . . 0 ☐ I do not use tobacco	1 ☐	2 ☐	3 ☐

11. How important do you think the following health behaviors are to your health?
(Check one box per line.)

		Not at all	A little important	Somewhat important	Very important
63	**Exercise**	1 ☐	2 ☐	3 ☐	4 ☐
64	**Nutrition**	1 ☐	2 ☐	3 ☐	4 ☐
65	**Weight**	1 ☐	2 ☐	3 ☐	4 ☐
66:67	**Alcohol use?** . . . 0 ☐ I do not drink	1 ☐	2 ☐	3 ☐	4 ☐
68:69	**Tobacco use?** . . . 0 ☐ I do not use tobacco	1 ☐	2 ☐	3 ☐	4 ☐

12. During the past 7 days, on how many days were you in the same room with someone who was smoking cigarettes? (Check the best answer.)

70 ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

13. During the past 7 days, on how many days were you in a car with someone who was smoking cigarettes? (Check the best answer.)

71 ☐ 0 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7

Appendix I (continued)

14. Please choose "True" or "False" for each statement below. (Check one box per line.)

		True	False
72	**I currently do not exercise**	1 ☐	2 ☐
73	**I intend to exercise in the next 6 months**	1 ☐	2 ☐
74	**I currently exercise** *regularly*	1 ☐	2 ☐
75	**I have exercised** *regularly* **for the past 6 months**	1 ☐	2 ☐
76	**I exercised** *regularly* **before my transplant-related diagnosis**	1 ☐	2 ☐
77	**I intend to exercise more**	1 ☐	2 ☐

Why do you want to exercise more? (Check all that apply.)

78:81	1 ☐ Improve health	1 ☐ My family/friends want me to	
79:82	1 ☐ Relieve illness symptoms	1 ☐ My doctor wants me to	
80:83	1 ☐ Set example for children	1 ☐ Other, specify: _____	

Skip to question 15 below.

What would make it difficult to exercise more? (Check all that apply.)

84:87	1 ☐ Stress/mood	1 ☐ Enjoy life as it is now
85:88	1 ☐ Fatigue	1 ☐ Pressure from family/friends to not change
86:89	1 ☐ No time	1 ☐ Other, specify: _____

On a scale of 1 to 10, with 1 being "Not at all confident" and 10 being "Completely confident," how confident are you in your ability to exercise more? (Check one.)

90-91 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

Not at all confident — Completely confident

15. <u>During the past week</u>, even if it was not a typical week for you, how much <u>total</u> time (for the <u>entire week</u>) did you spend on each of the following? (Check one box per line.)

		None	Less than 30 minutes	30 to 59 minutes	1 to 3 hours	More than 3 hours
92	**Stretching or strengthening exercises (range of motion, using weights, etc.)**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
93	**Walking for exercise**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
94	**Swimming for aquatic exercise**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
95	**Bicycling (including stationary exercise bikes)**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
96	**Other aerobic exercise equipment (stairmaster, rowing, skiing machine, etc.)**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐
97	**Other aerobic exercise, specify: _____**	0 ☐	1 ☐	2 ☐	3 ☐	4 ☐

Appendix I (continued)

16. How many servings of <u>fruit</u> do you usually eat each day? (Check the best answer.)

98 0☐ 0 1☐ 1 2☐ 2 3☐ 3 to 4 4☐ 5 to 6 5☐ 7 or more

17. How many servings of <u>vegetables</u> do you usually eat each day? (Check the best answer.)

99 0☐ 0 1☐ 1 2☐ 2 3☐ 3 to 4 4☐ 5 to 6 5☐ 7 or more

18. I intend to improve my nutrition.

100 1☐ True 2☐ False → **Skip to question 19 below.**

Why do you want to improve your nutrition? (Check all that apply.)

101:104 1☐ Improve health 1☐ My family/friends want me to
102:105 1☐ Relieve illness symptoms 1☐ My doctor wants me to
103:106 1☐ Set example for children 1☐ Other, specify: _____

What would make it difficult to improve your nutrition? (Check all that apply.)

107:110 1☐ Stress/mood 1☐ Enjoy life as it is now
108:111 1☐ Fatigue 1☐ Pressure from family/friends to not change
109:112 1☐ No time 1☐ Other, specify: _____

On a scale of 1 to 10, with 1 being "Not at all confident" and 10 being "Completely confident," how confident are you in your ability to improve your nutrition? (Check one.)

113-114 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

Not at all confident — Completely confident

19. When is the last time you used any type of tobacco (even 1 or 2 puffs, chew, etc.)?

115 1☐ Never → **Skip to question 28 on page 7.**
2☐ More than 12 months ago →
3☐ 6 to 12 months ago
4☐ 8 days to 6 months ago
5☐ 0 to 7 days ago

Appendix I (continued)

20. What kind of tobacco did/do you use? (Check all that apply.)

116-119 1☐ Cigarette 1☐ Chew/snuff 1☐ Cigar/pipe 1☐ Other

How many cigarettes did you smoke per day, on average in... (Check one box per line.)

	0	10 or less	11 to 20	21 to 30	31 or more
120 **the past 7 days**	1☐	2☐	3☐	4☐	5☐
121 **the past 6 months**	1☐	2☐	3☐	4☐	5☐
122 **the past 12 months**	1☐	2☐	3☐	4☐	5☐

21. I intend to be tobacco free (quit or remain quit).

123 1☐ True 2☐ False → **Skip to question 22 below.**

Why do you want to be tobacco free? (Check all that apply.)

124:127 1☐ Improve health 1☐ My family/friends want me to
125:128 1☐ Relieve illness symptoms 1☐ My doctor wants me to
126:129 1☐ Set example for children 1☐ Other, specify: _____

What makes it difficult to be tobacco free? (Check all that apply.)

130:133 1☐ Stress/mood 1☐ Enjoy life as it is now
131:134 1☐ Fatigue 1☐ Pressure from family/friends to not change
132:135 1☐ No time 1☐ Other, specify: _____

22. Have you quit using tobacco?

136 1☐ Yes → 137-144 **If yes, when did you stop?** __ __/__ __/__ __ __ __ (Month Day Year)

2☐ No

Skip to question 28 on page 7.

23. How soon after you wake up do you have your first cigarette/tobacco?

145 1☐ 0 to 5 minutes 2☐ 6 to 30 minutes 3☐ 31 to 60 minutes 4☐ More than 60 minutes

24. Do you find it difficult to refrain from tobacco in places where it is forbidden, e.g., in a church, on an airplane, at the movies, etc.?

146 1☐ Yes 2☐ No

Appendix I (continued)

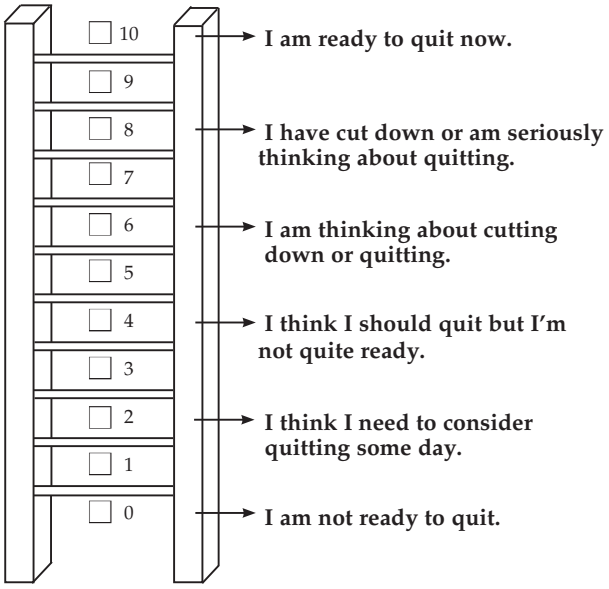
25. Do you smoke/use tobacco if you are so ill that you are in bed most of the day?

147 1 ☐ Yes 2 ☐ No

26. Readiness to quit tobacco

148-149 **Each rung on this ladder represents where various tobacco-users are in their thinking about quitting.**

Mark the box next to the number that indicates where you are now.



27. On a scale from 1 to 10, with 1 being "Not at all confident" and 10 being "Completely confident," how confident are you in your ability to quit tobacco? (Check one.)

150-151 ☐ 1 ☐ 2 ☐ 3 ☐ 4 ☐ 5 ☐ 6 ☐ 7 ☐ 8 ☐ 9 ☐ 10

Not at all confident — Completely confident

28. In the past <u>year</u>, how <u>often</u> do you have a drink containing alcohol?
(Check the answer that is correct for you.)

152 1 ☐ Never 2 ☐ Monthly or less 3 ☐ 2 to 4 times a month 4 ☐ 2 to 3 times a week 5 ☐ 4 or more times a week

How many drinks containing alcohol do you have on a <u>typical day</u> when you are drinking?

153 1 ☐ 1 or 2 2 ☐ 3 or 4 3 ☐ 5 or 6 4 ☐ 7 to 9 5 ☐ 10 or more

Appendix I (continued)

29. Below is a list of statements that other people with your illness have said are important. By marking one (1) response per line, please indicate how true each statement has been for you <u>during the past 7 days</u>.

	PHYSICAL WELL-BEING	Not at all	A little bit	Somewhat	Quite a bit	Very much
154	**I have a lack of energy**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
155	**I have nausea**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
156	**Because of my physical condition, I have trouble meeting the needs of my family**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
157	**I have pain**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
158	**I am bothered by side effects of treatment**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
159	**I feel ill**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
160	**I am forced to spend time in bed**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

	SOCIAL/FAMILY WELL-BEING	Not at all	A little bit	Somewhat	Quite a bit	Very much
161	**I feel close to my friends**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
162	**I get emotional support from my family**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
163	**I get support from my friends**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
164	**My family has accepted my illness**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
165	**I am satisfied with family communication about my illness**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
166	**I feel close to my partner (or the person who is my main support)**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
167	*Regardless of your current level of sexual activity, please answer the following question. If you prefer not to answer it, please check this box* 1 ☐ *and go the next section.*					
168	**I am satisfied with my sex life**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

Appendix I (continued)

By marking one (1) response per line, please indicate how true each statement has been for you during the past 7 days.

	EMOTIONAL WELL-BEING	Not at all	A little bit	Somewhat	Quite a bit	Very much
169	**I feel sad**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
170	**I am satisfied with how I am coping with my illness**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
171	**I am losing hope in the fight against my illness**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
172	**I feel nervous**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
173	**I worry about dying**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
174	**I worry that my condition will get worse**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

	FUNCTIONAL WELL-BEING	Not at all	A little bit	Somewhat	Quite a bit	Very much
175	**I am able to work (include work at home)**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
176	**My work (include work at home) is fulfilling**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
177	**I am able to enjoy life**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
178	**I have accepted my illness**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
179	**I am sleeping well**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
180	**I am enjoying the things I usually do for fun**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
181	**I am content with the quality of my life right now**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

	ADDITIONAL CONCERNS	Not at all	A little bit	Somewhat	Quite a bit	Very much
182	**I am concerned about keeping my job (include work at home)**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
183	**I feel distant from other people**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
184	**I worry that the transplant will not work**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

Continued next page...

Appendix I (continued)

By marking one (1) response per line, please indicate how true each statement has been for you during the past 7 days.

		Not at all	A little bit	Somewhat	Quite a bit	Very much
185	**The effects of treatment are worse than I had imagined**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
186	**I have a good appetite**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
187	**I like the appearance of my body**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
188	**I am able to get around by myself**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
189	**I get tired easily**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
190	**I am interested in sex**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
191	**I have concerns about my ability to have children**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
192	**I have confidence in my nurse(s)**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
193	**I regret having the bone marrow transplant**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
194	**I can remember things**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
195	**I am able to concentrate (e.g., reading)**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
196	**I have frequent colds/infections**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
197	**My eyesight is blurry**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
198	**I am bothered by a change in the way food tastes**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
199	**I have tremors**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
200	**I have been short of breath**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
201	**I am bothered by skin problems (e.g., rash, itching)**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
202	**I have troubles with my bowels**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
203	**My illness is a personal hardship for my close family members**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
204	**The cost of my treatment is a burden on me or my family**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

Appendix I (continued)

30. What was your employment status <u>before your illness</u>?

205
1 ☐ Employed full time
2 ☐ Employed part time because of my health
3 ☐ Employed part time for reasons other than my health
4 ☐ Unemployed because of my health
5 ☐ Unemployed for reasons other than my health
6 ☐ Retired because of my health
7 ☐ Retired for reasons other than my health

31. What was your employment status <u>right before your transplant</u>?

206
1 ☐ Employed full time
2 ☐ Employed part time because of my health
3 ☐ Employed part time for reasons other than my health
4 ☐ Unemployed because of my health
5 ☐ Unemployed for reasons other than my health
6 ☐ Retired because of my health
7 ☐ Retired for reasons other than my health

32. What is your <u>current</u> employment status?

207
1 ☐ Employed full time
2 ☐ Employed part time because of my health
3 ☐ Employed part time for reasons other than my health
4 ☐ Unemployed because of my health
5 ☐ Unemployed for reasons other than my health
6 ☐ Retired because of my health
7 ☐ Retired for reasons other than my health

33. Patients sometimes feel that having an illness makes contributions to their lives, as well as causing problems. Indicate how much you agree with each of the following.

Having had a serious illness...	Not at all	A little	Moderately	Quite a bit	Extremely
208 **has led me to be more accepting of things.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
209 **has taught me how to adjust to things I cannot change.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
210 **has helped me take things as they come.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
211 **has brought my family closer together.**.	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

Continued next page...

Appendix I (continued)

	Having had a serious illness...	Not at all	A little	Moderately	Quite a bit	Extremely
212	**has made me more sensitive to family issues.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
213	**has taught me that everyone has a purpose in life.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
214	**has shown me that all people need to be loved.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
215	**has made me realize the importance of planning for my family's future.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
216	**has made me more aware and concerned for the future of all human beings.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
217	**has taught me to be patient.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
218	**has led me to deal better with stress and problems.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
219	**has led me to meet people who have become some of my best friends**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
220	**has contributed to my overall emotional and spiritual growth.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
221	**has helped me become more aware of the love and support available from other people.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
222	**has helped me realize who my real friends are.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
223	**has helped me become more focused on priorities, with a deeper sense of purpose in life.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐
224	**has helped me become a stronger person, more able to cope effectively with future life challenges.**	1 ☐	2 ☐	3 ☐	4 ☐	5 ☐

225 **34. Comments:** _____

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Thank you for taking the time to complete the 1-year follow-up survey!

Question 29: Fact-BMT (Version 4). © US English 1987, 1997, David Cella, Ph.D.,

Question 33: Benefit Finding scale. Carver, CS & Antoni, MH (2004). Finding benefit in breast cancer during the year after diagnosis predicts better adjustment 5 to 8 years after diagnosis. Health Psychology, 26, 595-598.

Appendix I (continued)

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