Age differences in long-term adjustment and psychosocial outcomes in a large multi-site sample 5-10 years after heart transplant

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TRANSPLANT

A thesis submitted in partial fulfillment of the requirements for the degree of Master of Science
at Virginia Commonwealth University.

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Table of Contents

List of Tables

List of Figures

Abstract

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Research on age differences in heart transplant patients has focused primarily on medical

outcomes, with mixed findings regarding mortality and morbidity rates and limited research

regarding age differences in psychosocial and quality of life outcomes. To gain a more complete

understanding of psychosocial adjustment after heart transplant, this study examined age

differences in: satisfaction with quality of life, satisfaction with social support, depressive

symptoms, negative affect, symptom distress, stress related to heart transplant, overall health

functioning, coping strategies, and aspects of adherence. Results indicate that older patients,

compared to younger patients, report better adjustment and quality of life across numerous

outcomes 5-10 years after heart transplant. These findings are consistent with previous literature examining age differences in developmental changes with emotion regulation and coping. This study hopes to contribute to the discussion of age and heart transplant, highlighting the importance of considering quality of life in addition to medical outcomes.

Age differences in long-term adjustment and psychosocial outcomes in a large multi-site sample

5-10 years after heart transplant

Solid organ transplantation is undeniably a life-changing event, with a multitude of physical and psychological features to consider as part of the transplantation process. The success of these surgeries, however, relies on numerous outcomes following the surgery, including psychological adjustment, coping skills, and adherence to a treatment regimen or protocol. Given that heart disease is the number one leading cause of death for men and women in the United States (Heron et al., 2006), heart transplantation can be a life-saving measure for people whose heart disease develops into heart failure. According to the Organ Procurement and Transplantation Network (OPTN), in 2010, there were 2,334 heart transplants performed in the U.S., and this number of transplants completed has remained relatively stable since 1990. Of these 2,334 heart transplant patients, 1,430 patients were between the ages of 35 and 64, comprising well over half of the transplant population. Only 321 people at the time of the transplant were above the age of 65, comprising 13.8% of the transplant population. There were more heart transplants for children and teens under the age of 18 as there were for adults over 65 years. While there has been an increase in the percentage of older patients receiving heart transplant in the past 20 years (see Figure 1), this increase appears to have leveled off during the past several years. These rates are still low compared to rates of mortality due to heart failure, which is approximately 35 times more common in older adults relative to younger adults (Heron et al., 2006). Obviously, older adults are more likely to have comorbidities that may serve as contraindications to heart transplant, however it is interesting to note these discrepancies and trends in populations receiving heart transplants.

1
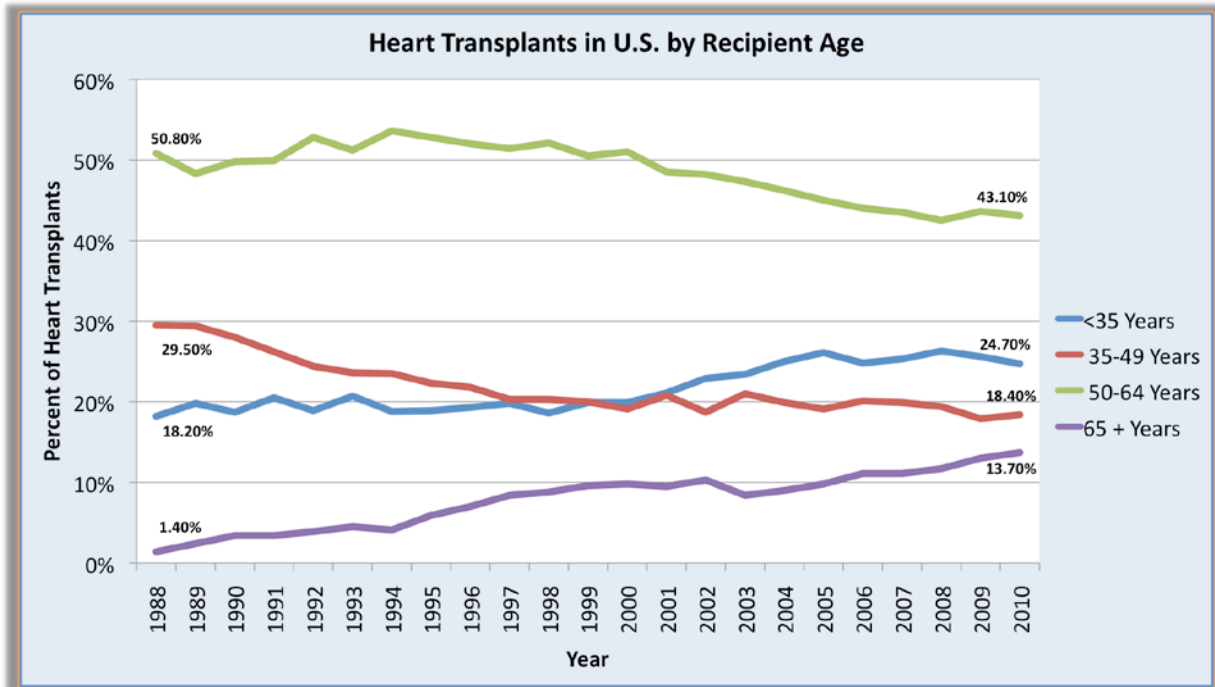
Figure 1. Data retrieved from the Organ Procurement and Transplantation Network online database. This distribution of heart transplants across age groups demonstrates that heart transplant rates for patients age 65 and older has increased since 1988. Over the past few years, however, distribution of heart transplants across all age groups has remained relatively stable.

It is well known that the U.S. population is aging (Gist & Hetzel, 2004). In 2008, people over the age of 65 represented 12.8% of the population, but they are expected to represent 19% of the population by the year 2030. Additionally, the health problems that older adults currently face include more chronic or gradually developing diseases, rather than acute, infectious illnesses (Larsen & Lubkin, 2009). Approximately 80% of older Americans have at least one chronic health condition (CDC & Merck Company, 2007), with hypertension as the most frequently occurring condition. One challenge to understanding health issues and outcomes is that the features influencing these outcomes can vary greatly depending on the population being addressed. Particularly between age groups, there can be differences in various psychological features of health, such as health beliefs, values, expectations for functioning following a disease, and motivations for treatment adherence. These differences are important for health

2

care professionals to understand, particularly in the case of a substantial stressor such as heart transplantation and recovery.

Given increasing life expectancies and improved health among older adults, it is important to continually evaluate standard practices and procedures regarding older adults and treatment options. There has been a continual increase in recommended guidelines for transplant recipient age cut-offs, however there are still disproportionately fewer older adults receiving heart transplants compared to younger adults. There may be various potential reasons for this discrepancy, including legitimate differences in outcomes for older patients, an unbalanced focus of clinical research regarding types of outcomes, or potentially there are misconceptions about how older patients will adjust to organ transplantation. The present study will not focus on identifying reasons for this discrepancy but instead depict the state of psychological adjustment for patients who have survived at least 5 years after heart transplant. Rather than focus on various predictors of adjustment, including patient age, the purpose of the present study is to provide more evidence and a further understanding of the psychological domains in which age differences exist.

Review of the Literature

   Survival rates and other medical outcomes. Based on OPTN data, it is evident that the number of adults over the age of 65 receiving heart transplants has increased over the past 15 years, although older adults generally have poorer physical health and more comorbid diseases than younger adults (Taylor et al., 2009). According to a study conducted by the International Society for Heart and Lung Transplantation (ISHLT) registry, many of the risk factors that were predictors for mortality at 1 year following heart transplant remained predictors at 5, 10, 15 and 20 years following surgery (Taylor et al., 2009). These predictors included a variety of

transplant-related variables, but increasing recipient age remained a significant risk factor for mortality at each of these follow-up stages.

In addition to the data from the ISHLT, several other studies have suggested that older patients have poorer medical outcomes following heart transplantation. A multi-site, large sample study (n = 911) used a multivariate approach and found that advanced age was a significant risk factor for death during the first year post-transplant (Bourge et al., 1993). An additional study demonstrated that adults over age 55 have higher rates of infection at 1 year post-transplant and lower survival rates at 5 years post-transplant compared to patients 55 years and younger (Borkon et al., 1999). According to the OPTN database, adults over the age of 65 have a 1-year survival rate of 84.3%, which is the second lowest survival rate of any age group. At 3 and 5 years post-transplant, older adults have the lowest survival rates (74.7 % and 65.3%), compared to the average survival rates across age groups (78.5% and 72.0%, respectively). These results provide evidence that older adults have poorer survival rates compared to other age groups, and that this trend remains the same with increasing years post-transplant.

Another study suggested that heart transplant outcomes for older patients are not as favorable compared to younger patients, finding that mortality and long-term survival rates for older patients were poorer than younger patients (Tjang, van der Heijden, Tenderich, Korfer, & Grobbee, 2008). A study examining long-term outcomes of heart transplantation found that older patients had significantly lower survival rates compared to younger patients, as well as lowered rate of malignancy and freedom from dialysis (Marelli et al., 2008). In a review in 2010, researchers note that older age may be a contraindication to cardiac transplant, and that age 65 should generally be considered the upper age limit for heart transplant (Mancini & Lietz, 2010). They also reference the increased mortality rates and lower long-term survival for older

4

patients, and they suggest that older transplant candidates should be considered with more scrutiny due to their limited reserve. As an example of a real-life application of these findings, there are transplant centers in the U.S. that explicitly state age cutoffs or age limitations regarding which patients the center will consider for heart transplant.

Contrary to this research, numerous studies have provided counterevidence suggesting that these older patients who receive heart transplants do not have poorer outcomes. A large single-center study (n = 702) found that older recipient age (patients above age 60) was not a risk factor for early or late death (Zuckerman et al., 2000). While this study used similar statistical techniques to the Bourge et al. (1993) study, Zuckerman and colleagues (2000) found opposing results regarding age as a risk factor for mortality. Another study examined long-term survival rates of patients over age 60 with induction therapy following heart transplantation from a single transplant center (Zuckerman et al., 2003). The researchers found no evidence for age differences in survival rates or incidence of severe infection compared to younger adults. An additional study conducted by Coffman and colleagues (1997) examined age differences in long-term survival and morbidity of heart transplant patients for 4 years following surgery. They found that 1-, 2-, 3-, and 4-year survival rates for younger patients (< age 60) and older patients (≥ age 60) were not significantly different. Return-to-work rates, number of hospitalizations and length of hospital stay also did not differ significantly between the older and younger patients. Other studies found similar results, in which older and younger patients had comparable survival rates up to 3 years post-transplant (Blanche et al., 1996) and 1, 5, and 10 years post-transplant (Demers et al., 2003).

Morgan and colleagues (2003) used a matched-sample design and compared older and younger heart transplant patients matched for sex, etiology of heart failure, UNOS status (United

5

Network for Organ Sharing status of medical urgency for transplant), and immunosuppression therapy era. They found no significant differences between the two patients groups in regards to 1-, 3-, 5-, and 10-year actuarial survival, overall hospital stays, or incidence of diabetes, hypertension, chronic obstructive pulmonary disease, or peripheral vascular disease. There were some significant medical differences between older and younger patients. For example, older patients had higher rates of prior myocardial infarctions and higher incidences of transplant coronary artery disease.

A recent retrospective study reviewed the United Network for Organ Sharing (UNOS) dataset to analyze outcomes for heart transplant recipients and examined age differences specifically (Weiss, Nwakanma, Patel, & Yuh, 2008). The study sample included 14,401 patients who received orthotopic heart transplant between 1999 and 2006. Their analyses showed that older patients ($\geq$ 60 years at time of transplant) had lower survival rates than younger patients, although they note that the cumulative 5-year survival rate differences between older and younger patients differed by only 6%. They also found that if older patients survived past the first year of transplant, their long-term survival only differed by 3% compared to the younger patients. Interestingly, the researchers discovered that older patients appeared to receive hearts from higher-risk donors who tended to be older and have higher rates of infection or diabetes. This concept of an "alternate list" of organs for older patients has been recommended by the ISHLT as a potential strategy for the future of organ allocation practices (Mehra et al., 2006). Weiss and colleagues (2008) however, suggest that the higher rates of mortality for the older patients found in their study may be a result of the high-risk donor organs allocated to older patients. The researchers concluded overall that the survival rates of older patients were acceptable, and heart transplant should not be restricted based on age. Additionally, the ISHLT's

2006 Guidelines for Care of cardiac transplant patients recommended that patients up to and including age 70 should be considered for cardiac transplantation, citing evidence of the comparable survival rates seen in the previously mentioned studies (Mehra et al., 2006). Thus, while some research suggests poorer outcomes for older adults following heart transplant, other research has found that regarding strictly medical outcomes, older adults may perform similarly to younger adults. Given these somewhat equivocal findings regarding morbidity and mortality rates, continued research is needed to examine various aspects of long-term heart transplant outcomes as a supplement and in conjunction with the medical outcome data.

Psychosocial outcomes. While research is unclear regarding age differences in morbidity and mortality outcomes, other research has found age differences in psychosocial functioning for those surviving patients. One study found that older patients reported better total quality of life and less psychological distress compared to younger patients at 3 and 4 years following heart transplantation (Coffman et al., 1997). Similar results were seen in a study that followed long-term heart transplant recipients who were still alive at more than 10 years after transplantation (Martinelli et al., 2007). These researchers found that while older patients (70 years or older) had significantly more impairment in a physical dimension of quality of life, their mental functioning regarding quality of life was similar to younger patients. Additionally, the older patient group reported significantly fewer depressive symptoms on the Beck Depression Inventory (BDI) than the younger group. There have also been similar findings in previous research using the same patient population as in the present study. Grady, Jalowiec, and White-Williams (1999) found that older age was a significant predictor of improved quality of life at 1 year following heart transplant. The authors attributed this finding to older patients having fewer non-health stressors due to their stage in life compared to younger patients. A study by

7

Rybarczyk et al. (2007) found that older heart transplant patients (60 years and older) are less depressed and report less negative affect than younger patients at 5 years following transplant surgery. Additionally, the older patients had lower depression scores compared to previously unpublished norms for nontransplanted heart failure patients of the same age group, while the young patients' depression scores were nearly the same as their same-aged nontransplanted heart failure patients. This suggests that younger heart transplant recipients return to pretransplant depression levels, while the psychological benefits for older adults are more durable and last for at least 5 years.

Some research has found that older patients have better psychological outcomes than younger patients with health stressors or other types of organ transplant. A study examining depression in female patients discovered that women aged 56 and older had significantly lower depression scores than those under age 56 after a major cardiac event (Plach, Napholz, & Kelber, 2003). Similar results were seen in another study that examined age differences in adjustment after 8 weeks of receiving a cancer diagnosis (Harrison & Maguire, 1995). The researchers found that younger patients had a significantly higher number of diagnosed depression and anxiety cases compared to the older patients. They also measured frequency of patient concerns and total number of concerns and discovered that younger patients had significantly higher concern scores compared to older patients. The researchers note the apparent better coping by the older participants, but they emphasized that a longitudinal observation of coping is needed. Another study measured quality of life following heart, liver, and lung transplant surgeries (Littlefield et al., 1996). These researchers found that patients who were physically active tended to be younger, while patients who functioned better psychologically tended to be older. Other studies suggest similar trends, that younger patients have better physical adjustment and

older adults have better psychological adjustment (Martinelli et al., 2007). A recent study examined psychological adjustment in patients nine years following cardiac-related surgery (Koivula, Hautama¨ki-Lamminen, & Astedt-Kurki, 2009). They found that being under age 65 was a common predictor for both long-term fear and anxiety and explained a significant portion of the variance in these outcome variables. While all of these previously mentioned studies address an aspect of age differences in adjustment following a health-related event, none have systematically examined age differences and their influence on comprehensive, long-term adjustment to heart transplantation.

Interestingly, advanced age may serve to benefit transplant patients in particular domains. Several studies have found a phenomenon in which older patients have significantly fewer rejection rates following transplantations than younger patients (Bradley, 2002; Coffman et al., 1997; Demers et al., 2003; Zuckerman et al., 2003). Immunosenescence, or the gradual deterioration of the immune system that occurs with natural aging, may actually be an explanation for the lower rejection rates in older adults following transplant (Renlund, Gilbert, & O'Connell, 1987). A recent study found that transplant recipients over age 60 had particular biomarkers of immunosenescence that made them less prone to reject kidney transplants (Trzonkowski et al., 2010). These researchers emphasized that medical professionals ought to take this immunosenescence factor into account when determining levels of immunosuppresion medication for older patients. Nonetheless, it appears that older adults may maintain certain advantages over younger adults in the years following transplant in both physical and psychological outcomes.

An important caveat to the interpretation of several of the previously mentioned findings is that older adults who participate in long term follow-up studies are a highly selected group of

9

patients that have survived through the first several years post-transplant. Studies that focus on psychological or psychosocial outcomes for heart transplant patients generally involve some follow-up period, since researchers are examining psychological outcomes ranging from the first year post-transplant through long-term follow-up several years after the transplant. Therefore, the patients who participate in the long-term follow-up studies are either patients who have survived up to that point, or they are healthy and feeling well enough to participate. These patients may have special psychological or physical characteristics that distinguish them from the other older transplant recipients who did not survive long enough or do not feel well enough to participate in the studies. The patients in these studies are a selected group, and may not accurately reflect the general pool of transplant patients. A highly selected group of participants can be a threat to external validity, or the ability to generalize the findings to the larger population (Kazdin, 2010). This is important to consider when examining various long-term research, since a limitation to these studies is that the participant sample only represents those patients who survive to participate in the study.

   Adherence. The terminology used to describe post-operative procedures has shifted somewhat over the past several decades. "Adherence" and "compliance" are often used interchangeably, though they have different connotations. According to Haynes (1979), compliance can be defined as "the extent to which a person's behavior (in terms of taking medication, following diets, or executing lifestyle changes) coincides with medical or health advice." This definition has been criticized since it places the patient in a very passive role, minimizes his or her role as a decision-maker, and suggests that health care is authoritarian (Eisenthal, Emery, Lazare, & Udin, 1979). Adherence, on the other hand, suggests a more active, collaborative interaction between the provider and the patient. Although the term patient

10

compliance (commonly seen in the context of a "non-compliant patient") is often seen in medical literature (Feinstein, 1990), adherence reflects a more patient-centered perspective of health care. This paper will use the term *adherence* in the place of the word *compliance*.

Adherence to post-transpant medical regimen is a critical component of long-term post-transplant care. Nonadherence may lead to acute rejection episodes, loss of the transplanted organ, or even death. Additionally, patient nonadherence can be frustrating for transplant center personnel and other members of the transplant team, particularly since an organ that is rejected due to nonadherence could have been given to another patient on the waiting list (Laederach-Hoffman & Bunzel, 2000). Regarding heart transplant, one study estimated nonadherence rates as high as 37% for exercise, 34% for monitoring blood pressure, 20% for immunosuppressive medication, 19% for smoking, 18% for diet, 9% for clinical attendance, and 6% for heavy drinking (Dew, Roth, Thompson, Kormos, & Griffith, 1996). The most important domain for adherence is with medication adherence, or immunosuppressive drugs, which are necessary to prevent rejection episodes. Self-reported reasons for medication nonadherence include disliking the side effects of medication, cost of medications, insufficient family support, low self-esteem, or simply forgetting to take the medications (Laederach-Hoffman & Bunzel, 2000).

There is some evidence to suggest older patients show better adherence to their post-surgery medical regimen. One study examined renal transplant patients (n = 34) at 5-6 years post-transplant (Gremigni et al., 2007). Adherence was measured by a self-report scale evaluating frequency of taking medication and difficulty taking medication exactly as prescribed. The researchers found that age was a predictor of adherence, with younger patients being less likely to adhere than older patients. They also discovered that participants who used an active coping style and perceived less autonomy in their treatment management were less likely to take

11

their medications. These three variables (age, autonomy, and active coping) accounted for 65% of the variance of adherence to medication.

In a study examining psychosocial variables and adherence in heart failure patients (Evangelista, Berg, & Dracup, 2001), researchers found that medication adherence was significantly higher for patients age 60 and older than those under age 60. They also discovered that mental health, physical health, and neuroticism were significant predictors of overall adherence, with better mental health, physical health, and lower neuroticism predicting better adherence rates. Thus, it appears that the variations in psychological adjustment and well being may be related to the important post-operative medical regimen adherence. These findings again highlight the notion that older patients may have more sought after adherence behavior in addition to the improved psychological outcomes.

There are various theoretical models for understanding adherence and conceptualizing why people have particular health behaviors that may help explain these findings. One of these theories is the Health Belief Model (HBM), which suggests that personal beliefs and perceptions about a disease influence health behavior (Becker, 1974; Glanz, Rimer, & Lewis, 2002). Beliefs about strategies to decrease disease occurrence can also impact health behavior in this model, which may be useful in examining factors that relate to medical regimen adherence. This model includes four primary constructs that can be used to explain health behavior; the perceived seriousness of a disease, perceived susceptibility or personal risk, perceived benefits of adopting a new behavior, and the perceived barriers to change.

There are several other factors that may also influence these constructs. *Modifying variables* are individual characteristics, such as education level or past experience, which influence personal perceptions. *Cues to action* are events or things that move people to change

12

their behavior, including advice from others or the illness of a friend or family member. Rosenstock, Stretcher, and Becker (1988) added *self-efficacy* to the original four constructs, emphasizing the idea that a person's belief of his or her capability to complete a new health behavior will influence the likelihood that behavior is performed. The self-efficacy model itself has been used to explain health behavior (Bandura, 1997). Bandura suggests that health behavior is a result of beliefs in one's ability to carry out a certain action and the anticipated consequences of that behavior. Perceived self-efficacy may be influenced by a variety of variables as well, including previous history, persuasion or support by others, and an individual's physical and emotional state. While Bandura's self-efficacy model (1997) focuses on relatively intraindividual features, the HBM encompasses a much wider range of factors. The HBM is quite comprehensive in that it accounts for a broad scope of influences, ranging from unique personal beliefs about oneself and a disease to larger psychosocial factors. Age may play a role as a modifying variable in this model and serve as a proxy for past experience, with the presumption that older adults have had more experience with health and health management. They have likely also experienced more *cues to action* than younger adults, and older patients who often witness same-age peers or family members becoming ill may be continually motivated to adhere to their medical regimen. Lastly, older adults may have higher self-efficacy regarding their ability to carry out certain health behaviors, again due to their experiences and knowledge of how their body responds to illness.

Another theory that can explain health behavior is the common-sense model (CSM), (Hale, Treharne, & Kitas, 2007; Leventhal, Meyer, Nerenz, 1980; Meyer, Leventhal, Gutmann, 1985). Unlike the HBM, the CSM focuses more on illness representations. The CSM posits that a person's "lay" beliefs about an illness are combined with existing beliefs, which in turn guide the

13

person's understanding of symptoms and resulting coping behavior. There are five main components of the CSM: 1) identity, or label given to a disease and the symptoms associated with it; 2) cause, or individual belief of perceived cause of condition; 3) duration, or expected time-line for how long the condition may last; 4) consequences, or expected outcome and impact of the disease; and 5) curability/controllability, or beliefs about whether the disease can be managed and an individual's degree of influence.

An older patient may perceive or represent heart transplant differently from a younger patient, which according to the CSM, would influence his or her health behavior. First, an older patient might label or identify heart transplant as an opportunity for improvement in quality of life or extension of healthy years, versus a younger patient who may hold a more negative connotation with the heart transplant since illness and disease do not fit the expectations for health of a younger person. Older patients may also have more realistic expectations for duration of recovery period than younger patients, again since older patients generally have more experience with illness and recovery. Additionally, younger patients may have a more difficult time adjusting to life after heart transplant compared to older patients due to unexpected consequences or impact of the surgery. Presumably, fewer older patients are working when they have the surgery, while many of the younger patients may still be holding jobs. Therefore, younger patients' expectations for functioning or ability to return to previous levels of activity may be higher due to financial responsibilities and desire for a return to normal functioning.

Ultimately, there are numerous ways in which people experience an illness or disease, and certain modifying variables, such as age, can impact these perceptions. Understanding which populations may experience heart transplant differently can have significant implications for important health-related behaviors. Medical regimen adherence, in particular, cannot be

14

underestimated in terms of medical outcomes following transplant surgery. One review found that poor adherence or nonadherence was responsible for up to 25% of patient deaths during the initial recovery period following transplant (Laederach-Hofmann & Bunzel, 2000). This study found that overall nonadherence rates ranged from 20-50%, demonstrating that assumptions about transplant patients as highly motivated may not be accurately reflected in their health behaviors. As suggested from the previously reviewed models, health behavior is multifaceted, but there are several components in which age might serve as a proxy and could be used to explain age differences in adherence rates.

For heart transplant in general, where the ultimate goal is to improve quality of life and increase life expectancy by a number of years, it is also important for consider the element of long-term adjustment. Certain important health-related behaviors, such as nonadherence rates, tend to increase over time (Haynes, 1999), since it is suggested it is easier to make behavior change for a short-term rather than a long-term period. On one hand, one might expect that adherence rates increase over time as the patient becomes more familiar and accustomed to the rigors of the post-transplant regimen. Research, however, shows the exact opposite trend, with difficulty with adherence increasing over time. Dew et al. (1996) found that patients reported increases in difficulty following physicians' instructions at 2, 7, and 12 months post-transplant. As one might infer, the percentage of patients reporting multiple problems with the medical regimen increased over the follow-up period (41.4% at 2 months, 60.9% at 7 months, and 77.9% at 12 months). Therefore, it is important to examine adherence rates as well as other psychosocial outcomes at a long-term follow-up period to better understand long-lasting trends in adjustment.

15

Stress and coping. The time period immediately following heart transplant, as well as for several years after, can undoubtedly cause stress. There are numerous adjustments that need to be made, such as the acceptance of the patient role, managing finances, adherence to the medical regimen, and concern with returning to work or physical rehabilitation (Olbrisch, Benedict, Ashe, & Levenson, 2002). Although each patient may go through the same surgery and are instructed to follow a similar post-operative regimen, certain individual factors can impact the experience and management of stress that accompanies this recovery period.

Some research has shown that older adults tend to report fewer stressful life events than younger adults (Paykel, 1983), and they also report fewer stressors in general. Chiriboga (1997) examined four groups of adults at different stages of life and asked them to rate how often they were hassled by a particular stressor. The four groups included high school seniors (n = 52), newlyweds (n = 50), parents in early middle age about to be "empty nesters" (n = 54), and later middle-age adults within two to five years of retirement (n = 60). The researcher found that the retirement and empty-nest participants were less hassled and reported fewer life events than the younger participants.

Another study found that younger and middle-aged adults reported more daily stressors than older adults (Almeida & Horn, 2004). These researchers took a sample (n= 1031) from the National Survey of Midlife in the United States (MIDUS) and conducted telephone interviews with the participants. They used a semi-structured interview to assess frequency and content of daily stressors. Results showed that compared to young and midlife adults, older adults reported less frequent stressful days, fewer stressors, and described their stressors as less severe. Additionally, the frequency of interpersonal tensions decreased as age increased, however older

16

adults had a higher proportion of stressors involving a close friend or relative compared to the other age groups.

The previous sets of findings make intuitive sense when considering that younger and middle-aged adults may have more daily occupational responsibilities or stressors from raising a family. On the other hand, older adults are more likely to face health problems, including chronic illness that requires daily management, or even bereavement of spouses and friends (Aldwin, 2007). In considering these findings, some researchers have wondered perhaps the older adults experience and cope with the stressors in a more adaptive manner. Charles et al. (2010) examined differences in daily stressors and positive events and their impact on emotional experience among older women (n = 101, 63-93 years old). They hypothesized that the older women would experience less emotional reactivity than the younger women in the participant sample. They instead found that participants across age groups reported similar increases in negative affect in response to a stressor. The oldest women, however, reported less frequent negative affect and fewer stressors, and the researchers found that the age differences in negative affect were fully mediated by the decrease in daily stressors. They suggested that perhaps older adults are more effective at regulating difficult situations early on, and thus would manage a particular stressor so effectively that they would not even report it as a stressor that caused distress.

In addition to age differences in reporting stressful events, there is also evidence that older adults may cope with stress differently from younger adults. A large study using 1,000 interviews of middle-aged to older men from the Normative Aging Study (NAS) found that older men reported fewer negative emotions, fewer problems, and appraised the problems as less stressful than the younger men (Aldwin, Sutton, Chiara, & Spiro, 1996). They also reported

17

fewer explicit coping strategies, but since there were no age differences in perceived coping efficacy, the researchers interpreted the findings to suggest that the older men were more effective copers. Additionally, the researchers speculated the prospect of a temporal change in the nature of stress with increasing age. Perhaps as stressors become more chronic rather than episodic, older adults utilize more "management strategies" rather than coping strategies, for example by rearranging their lives or daily experiences to avoid opportunities where stressful problems might be present.

Other studies have suggested differences in types of coping with increasing age. One study found that older adults used proportionately more intrapersonal, passive, emotion-focused forms of coping while the younger adults used more interpersonal, active, and problem-focused forms of coping (Folkman, Lazarus, Pimley, & Novacek, 1987). Another study found similar results, in which older adults were less likely to use emotional expression or information seeking in order to cope with an illness than middle-aged adults (Felton & Revenson, 1987). When examining these previously reviewed studies, research methodology is an important consideration. Aldwin (1990) discusses that many life event inventories used in stress and coping research include daily stressors that are more relevant to younger adults, such as challenges with marriage, children, and occupational responsibilities. Both Folkman and colleagues (1987) and Felton and Revenson (1987) used various self-report stress and coping scales that do not specify age considerations regarding the content. The findings from these studies may have been influenced by the proportionately more relevant scale content for the younger adults.

An additional reason why the older patients may adjust differently to heart transplant may be due life experiences. The inoculation hypothesis suggests that prior experience with a negative event provides an inoculation from a strong emotional response when experiencing a

18

similar situation in the future (Eysenck, 1983). Therefore, an older patient may experience surgery, complicated medical regimens, and general health-related stress as less stressful since he or she is more likely to have experienced similar events in the past compared to a younger patient. Several studies of older adults following a natural disaster have found that older adults who were previously exposed to a natural disaster reported less anxiety (Norris & Murrell, 1988) and fewer depressive symptoms (Knight, Gatz, Heller, & Bengtson, 2000) than older participants without previous exposure. Another study compared older and younger participants on short-term post-traumatic symptoms following an earthquake, and found that the older participants' PTSD symptoms dissipated significantly quicker than the younger participants' symptoms (Kato, Asuki, Miyaki, Minakawa, & Nishiyama, 1996). This body of research can be expanded in understanding why older adults may fare better than younger adults following a major surgery, given that older adults have generally had more experience with health problems and recovery procedures.

Another reason for the older patients' better adjustment may be due to age-related changes in emotion regulation. Various studies have demonstrated that there are important changes in the emotion domain as people age. Lawton, Kleban, Rajagopal, and Dean (1992) studied a large sample of younger, middle-aged, and older adults, and found that emotional intensity decreased as age increased. Additional studies have found that this decrease in emotional intensity and expressivity is more apparent for negative emotions (Barrick, Hutchinson, & Deckers, 1989; Carstensen, Gottman, & Levenson, 1995). One study using a large, ethnically diverse sample demonstrated that older participants reported greater emotional control and fewer negative emotional experiences compared to younger participants (Gross et al., 1997). These researchers interpreted their results to suggest that older adults' greater emotional

control is adaptive and allows them to experience positive emotions more frequently, while diminishing the occurrence or intensity of negative emotions. One theoretical explanation for these findings is the socioemotional selectivity theory (Carstensen, Isaacowitz, & Charles, 1999). This is a motivational theory that posits people are more motivated to pursue emotionally meaningful goals as they age, which they achieve through improved emotion regulation. An additional body of research has coined the term "positivity effect", which finds a shift from a preference for negative information in youth to a preference for positive information later in life (Carstensen & Mikels, 2005). Thus, general age changes with emotional experience may explain some of the improved psychological adjustment and decreases in negative affect found in the previously cited studies.

The social support systems of older and younger adults also differ from each other. As explained through socioemotional selectivity theory (Carstensen et al., 1999) older adults are motivated to pursue emotionally meaningful relationships, and they tend to selectively maintain these relationships while discarding less important social contacts. As a result of this pruning process, older adults tend to have smaller social networks that are composed of close social partners, relative to the social networks of younger adults (Carstensen, Fung, & Charles, 2003). This reduction of peripheral social contacts has a benefit for older adults, since their social network, though small, is made up of emotionally close people. Carstensen and colleagues (2003) note that these preferred social partners are more likely to provide social connectedness and facilitate emotionally meaningful experiences, and older adults report feel quite satisfied with their social networks.

Some of these age-related changes in social support are seen in heart-related health literature. One study examined social support use among older adults with chronic heart failure,

and found that men under the age of 65 perceived less support than other groups in the study (Bennett et al., 2001). They also found that changes in social support significantly predicted changes in health-related quality of life, suggesting that social support and perceptions of support may play an important role in some psychosocial outcomes. Other research has also demonstrated the importance of social support in organ transplant. Bunzel & Laederach-Hoffman (2000) reviewed transplant studies to examine predictors of post-transplant noncompliance, and they found that poor social support was a predictor of post-transplant adherence difficulties. Social support is an important psychosocial element to consider in the transplant process, and patients' levels of social support should always be evaluated on an individual basis. However, age-related changes in motivations for emotionally meaningful social experiences may increase the possibility for older adults to have more satisfying and better social support than younger adults.

An additional consideration in regards to age differences in health-related stress is the notion of "being off schedule" as a potential stressor. Neugarten (1976, 1979) suggests that there is a socially prescribed timetable for major life events, and unanticipated life events that occur "off schedule" can be a source of distress. Illness and health concerns in older age are considered anticipated life events, and therefore do not cause what Neugarten (1979) terms "psychiatric crisis." With unexpected and unanticipated events, Neugarten (1976) explains that the event cannot be rehearsed, a person cannot conduct any "grief work", and there is no reconciliation with how the event fits into the continuity of the life cycle. Based on Neugarten's ideas, people in midlife with serious health concerns, such as those requiring a heart transplant, might enter into the surgery with an already heightened level of distress. They may feel incongruence between their expectations for a schedule of life events and their current health

21

state, whereas the older adults who are encountering health problems "on time" might not feel the same distress.

Statement of the Problem

Rationale. Numerous studies have examined age differences in medical outcomes for heart transplant patients, and a relatively smaller body of research has explored long-term psychological adjustment to heart transplant. Several studies have found age differences in adherence and psychosocial outcomes after a cardiac event (Bennett et al., 2001; Evangelista et al., 2001; Koivula et al., 2009), but these results were generally incidental findings in which the researchers were not focusing on age differences directly. Other previous studies using the same subset of data in the present study have reported on secondary findings of age differences in depression (Rybarczyk et al., 2007), negative affect (Rybarczyk et al., 2007) and quality of life (Grady et al., 2005), but again none of the previous studies focused on comprehensive examination of age differences in heart transplant outcomes. There are various theoretical bases for understanding how age may play a role in adjustment to heart transplant, including differences in emotion regulation and experiences of stress, coping styles, social support, and even more existential considerations of major health events at certain stages in life.

Additionally, several of the previously reviewed studies involved patients drawn from a single transplant center (Borkon et al., 1999; Coffman et al., 1997; Demers et al., 2003; Littlefield et al., 1996; Marelli et al., 2008; Martinelli et al., 2007; Morgan et al., 2003; Tjang et al., 2008). This study will include data gathered from heart transplant patients who received treatment at four different transplant centers located across the U.S. One advantage to this multi-site study is that the external validity of the study is strengthened and the results can be more confidently generalized to the larger population of heart transplant recipients (Kazdin, 2010). By

22

including participants from multiple sites in a single study, there is a reduced chance that results will be influenced by certain participant sample characteristics which are unique to one geographic location or stimulus characteristics that distinguish one transplant center from another.

The purpose of the present study was to examine age differences in long-term adjustment to heart transplant from a psychological perspective in an effort to supplement and support the bodies of research regarding both medical and psychosocial outcomes for heart transplant patients. In the 2006 Guidelines for Care of Cardiac Transplant Patients published by the International Society for Heart and Lung Transplantation, it was recommended that patients ≤ 70 years of age can be considered for heart transplantation (Mehra et al., 2006). Additionally, they recommend that carefully selected patients over the age of 70 may be considered for heart transplantation if they meet specific criteria. In an effort to further support these recommendations, this study contributes to the literature by focusing primarily on age differences in several aspects of psychosocial adjustment to heart transplantation.

Hypotheses. The study aims in the present study were to compare older and younger heart transplant patients on numerous psychosocial outcomes 5-10 years after their transplant. In considering the previously reviewed literature and the rationale for the present study, the following hypotheses for the present study are:

Compared to younger patients, patients over the age of 65 at time of follow-up (at least age 60 at time of transplant) will have 1) higher satisfaction with quality of life, 2) higher satisfaction with social support, 3) lower levels of negative affect, 4) less depression, 5) less symptom distress, 6) less self-reported stress related to the heart transplant, 7) higher levels of

23

overall functioning, 8) more positive coping strategies, 9) less difficulty with medical regimen adherence, and 10) better adherence behavior.

Method

Participants

Heart transplant patients who participated in this study were from a large, multi-site, prospective study of quality of life outcomes between 5 and 10 years after the transplantation. The non-random sample was drawn from 1,437 patients who received heart transplants between July 1, 1990 and June 30, 1999 at one of four medical centers in the United States, each with IRB approval. Each of these four centers were active participants in the Cardiac Transplant Research Database (CTRD). At the time of the start of the original study, there were 884 patients between 5 and 10 years post-heart transplantation that were eligible for study recruitment. Of the patients that were not eligible for study recruitment ($n = 553$), 386 patients died prior to consent and 167 patients transferred their care to another institution. Study inclusion criteria included the following: participants at least 5 years postorthotopic heart transplant; at least 21 years old; able to read and write English as demonstrated by the ability to pass the subtest of the Wide Range Achievement Test (Wilkinson, 1993); physically able to participate in the study; and able to give informed consent. While 597 patients provided informed consent, 555 patients provided both informed consent and completed one or more questionnaire booklets. Thus, the final sample size for this study was 555 patients who received heart transplantation and completed the booklet of self-report instruments at least once between the 5 and 10 years after transplant.

Secondary analysis of this data set was approved by Virginia Commonwealth University's Institutional Review Board under the study title: Age Differences in Long-Term Adjustment to Heart Transplant.

24

Procedure

Each of the four medical centers that participated in the original study received separate institutional review board approval for conduct of the original study and participation in the CTRD. Qualified patients were contacted, and those who volunteered consented face to face during a medical visit or were mailed an informed consent form. After written consent was obtained, patients were given the booklet of questionnaires and requested to return the booklet within 2 to 3 days using a stamped and addressed envelope. Participants were sent the booklet of self-report instruments every 6 months, based on the anniversary of their transplant, between 5 and 10 years after transplantation. Booklet data ranging from 5 to 10 years post-transplant will be included in this report. Since participants completed more than one booklet between 5 and 10 years post-transplant, only data from each patient's first completed booklet was included in these analyses (M = 6.16 years post- transplant, SD = 1.40 years post-transplant, minimum = 5 years post- transplant, maximum = 10 years post- transplant). Preliminary analyses found there was a main effect of age group on average time of follow up, $t(553)$ = 3.16, p = .002, with the older patient completing their first booklet earlier (M = 5.87 years, SD = 1.24) than the younger patients (M = 6.28 years, SD = 1.44). This finding suggests that the older patients were more likely to complete their first booklet that was mailed to them than younger patients. Additionally, the study sample paralleled the national trend toward transplanting more older adults in recent years, and the present sample found that approximately two thirds of the older participants received their transplant during the last 3 years of the 9 year recruitment period. An analysis of covariance demonstrated that when *date of transplant* was assigned as a covariate, there were no differences between older and younger patients' in years since transplant.

If booklets were returned within 2 weeks of mailing, patients were contacted to encourage completion and return of the booklets. Patients were compensated $10 for each booklet that was returned. All booklets were sent to Rush University Medical Center for data screening and cleaning before being mailed to the University of Alabama for computer data entry. The research coordinator contacted each patient in an effort to clarify any uncertainties in missing or unclear data.

Measures

Participants completed 12 self-report quality of life instruments in the original study at 5-10 years after heart transplant. Nine of the instruments and the chart review will be used in analyses for this study, and they will be chosen based on adequate levels of psychometric support and their relevance to the research question. Additional clinical information about patients was gathered based on two chart review methods and associated CTRD forms. The instruments are described below and included in the Appendix.

Quality of Life Index (QLI) Cardiac Version-IV (Ferrans & Powers, 1985). The QLI has 35 items that measure importance of and satisfaction with various aspects of life. There are four subscales in the QLI: health/functioning, socioeconomic, psychological/spiritual, and family. Items are rated on a 6-point scale as follows: for importance, 1 = *very unimportant* and 6 = *very important*; for satisfaction, 1 = *very dissatisfied* and 6 = *very satisfied.*

Previous studies have reported adequate reliability and validity for this tool (Ferrans & Powers, 1992). Internal consistency reliability was established for the entire QLI (alpha = .93) and the four subscales of health/functioning, socioeconomic, psychological/spiritual, and family (alphas = .89, .78, .88, .70, respectively) (Dougherty, Dewhurst, Nichol, & Spertus, 1998). Two

26

week test-retest reliability was adequate for the entire scale ($r = .79$) and the four subscales ($r = .72$, $r = .68$, $r = .76$, $r = .69$, respectively.

Convergent validity was established through a correlation between overall QLI and scores on a life satisfaction assessment ($r = .77$) (DeVon & Ferrans, 2003). Convergent validity was also supported through significant correlations found between QLI subscales and other quality of life assessments. The health and functioning subscale of the QLI was correlated with the physical limitation of the Seattle Angina Questionnaire (SAQ) ($r = .47$, $p < .001$), the physical component of the Short Form (36) Health Survey (SF-36) ($r = .46$, $p < .001$), as well as the general health component of the SF-36 ($r = .71$, $p < .001$) (Dougherty et al., 1998). The psychosocial/spiritual subscale of the QLI was correlated with SF-36 mental health scale ($r = .57$, $p < .001$), emotional role functioning scale ($r = .41$, $p < .001$), and the social functioning scale ($r = .49$, $p < .001$).

Assessment of Problems with the Heart Transplant Regimen (Grady, Jalowiec, & White-Williams, 1998). This tool measures difficulty with adherence (part A) and actual adherence (part B) with various aspects of the heart transplant medical regimen. Both parts A and B assess the following aspects of the heart transplant regimen: immunosuppressants, nonimmunosuppressants, diet, exercise, not smoking, taking vital signs, calling with problems, clinic attendance, and getting lab and other tests done. Patients indicate how much difficulty they have had with adherence (1 = *no difficulty*, 2 = *a little difficulty*, 3 = *moderate difficulty*, 4 = *a lot of difficulty*) and how adherent they have been (1 = *all of the time*, 2 = *most of the time*, 3 = *some of the time*, 4 = *hardly ever*).

Psychometric support for this instrument was adequate and assessed through test-retest reliability, content validity, and concurrent validity (Grady, Jalowiec, & White-Williams, 1998).

27

Test-retest reliability (n = 185) was established with significant correlations between total difficulty with compliance at one year and two years after transplantation ($r = .46$, $p < .0001$) and total compliance at one year and two years after transplantation ($r = 0.59$, $p < .0001$). The scale developers used a broad literature base, empirical base, and research team expertise to select items for the tool, which they identified as a support of scale content validity.

Concurrent validity was established through significant correlations between ratings of difficulty following the heart transplant regimen and various psychosocial variables; for example, greater self-reported difficulty following the exercise portion of the regimen was significantly correlated with greater symptom distress ($r = .34$, $p < .0001$), more disability ($r = .34$, $p < .0001$), and more self-care distress ($r = .32$, $p < .0001$). Concurrent validity was also supported through significant correlations between self-reported compliance and other psychosocial variables; for example, more compliance with taking the anti-rejection medications was significantly correlated with more satisfaction with health ($r = -.22$, $p = .018$) and less self-care stress ($r = .32$, $p < .0001$). Lastly, the instrument was found to be sensitive to change in patient responses. Difficulty with following the transplant regimen increased significantly from six months to two years after transplantation for exercise ($t = 4.17$, $p < .0001$) and diet ($t = 2.64$, $p = .009$). Additionally, compliance decreased significantly from six months to two years after transplantation for total compliance ($t = 2.59$, $p = .01$), diet ($t = 3.10$, $p = .002$), and exercise $t = 5.06$, $p < .0001$) The instrument did not have internal consistency reliability, which the tool developers suggest could be expected given that the post-transplant health care regimen has different components. They explain that compliance related to taking medications is not necessarily related to compliance with a dietary regimen, for example, since it may be more difficult to change dietary behaviors than change types of prescribed medications.

Sickness Impact Profile (SIP; Bergner, Bobbitt, Carter, & Gilson, 1981). The 136-item SIP is a widely used instrument that measures functional ability (Bergner et al., 1981). It is designed to reflect a participant's perception of his or her performance of the activities involved in carrying on his or her life. The SIP assesses the extent of disability in 12 areas of physical and psychosocial functioning (sleeping, eating, job, self-care, mobility, ambulation, home management, recreation, social interaction, emotional reactions, cognitive functioning, and communication), with higher scores indicating greater disability. Items were weighted by Bergner et al. (1981) on the basis of the severity of disability for each item, and higher scores equal greater levels of disability. SIP scores in the 12 areas of functioning can be combined to indicate overall disability, physical disability, and psychosocial disability.

The SIP has extensive psychometric support in the literature (Bergner et al., 1981; Bergner, Bobbitt, Pollard, Martin, & Gilson, 1976; Kaplan, 1985; Pollard, Bobbitt, Bergner, Martin, & Gilson, 1976). Test-retest reliability was assessed with different administration procedures with a variety of subjects differing in type and severity of functioning. The overall test-retest reliability of scores was adequate (r = .75-.92) (Bergner et al., 1981). Additionally, internal consistency of scores was high, with Cronbach's alpha ranging from .94 to .97 across two field trials.

Convergent and discriminant validity were evaluated using a multitrait-multimethod methodology, which demonstrated that SIP score reproducibility was higher than reproducibility of other measures, and that the SIP scores were highly related to the criterion measures that were considered most reflective of the construct of sickness (Bergner et al., 1981). The tool developers also examined clinical validity by determining the relationship between SIP scores and clinical measures of disease. The disease categories chosen were total hip replacement,

hyperthyroidism, and rheumatoid arthritis, and correlations between three clinical measures of these diseases and the SIP were adequate ($r = -.81$, $r = .41$, $r = .66$, respectively) (Bergner et al., 1981). Lastly, criterion validity was supported through examining correlations between the SIP scores and various criteria. Moderate correlations were found between SIP scores and: self-assessment of dysfunction ($r = .69$), self-assessment of sickness ($r = .63$), clinician assessment of dysfunction ($r = .50$), clinical assessment of sickness ($r = .40$), and the NHIS (National Health Interview Survey Index of Activity Limitation, Work Loss and Bed Days) ($r = .55$). SIP scores are expressed as a percentage of the sum of the weights of the affirmatively checked statements divided by the sum of all factor weights under analysis. The general adult population has a score of 5, while a SIP score of 20 indicates the need for substantial daily care and a score of 30 indicates the need for nearly complete care (Lipsett et al., 2000).

Social Support Index (SSI; Grady et al., 1995). The SSI measures structural aspects of the support network, functional types of assistance received, and satisfaction with support. The SSI also includes two subscales of functional support; tangible and emotional. These subscales are based on satisfaction with the support received for 15 illness-related tasks (Grady et al., 1995). Satisfaction with support was rated on a 4-point scale, with higher scores indicating less satisfaction with social support (1 = *very satisfied*, 2 = *fairly satisfied*, 3 = *somewhat dissatisifed*, 4 = *very dissatisfied*). Satisfaction with support was derived by summing scores for each subscale item and dividing by the number of tasks for which a person received help. The SSI has adequate psychometric support (Grady et al., 1995). Cronbach's alpha for the total measure (n = 260) was acceptable ($r = .84$). Alphas for the subscales measuring tangible support and emotional support were also adequate for establishing internal consistency ($r = .78$ and $r = .69$, respectively).

Heart Transplant Symptom Checklist (HTSC; Grady, Jalowiec, Grusk, White-Williams, & Robinson, 1992). This tool measures the presence and severity of 89 adverse symptoms related to heart failure, heart transplant, medications, and complications. These items were compiled through a literature review and the clinical expertise of clinicians experienced in the care of these individuals. Participants indicate whether they have had the symptom in the past 6 months and, if so, rate how bothered they were by each symptom on a scale of 0–3 (0 = *not bothered at all*, 1 = *slightly bothered*, 2 = *moderately bothered*, and 3 = *very bothered*). The tool has six subscales of symptoms: cardiopulmonary, gastrointestinal, genital–urinary (sexual and urinary functioning), neurological (cognitive deficits, lethargy and fatigue, sensory deficits, weakness, pain), dermatological (physical appearance and discomfort symptoms), and psychological/emotional.

The HTSC was found to be a reliable and valid tool in heart transplant recipients (Grady et al., 1992; Jalowiec et al., 1992). In heart transplant recipients (n = 260), Cronbach's alpha for the entire tool was .95 and ranged from .68 to .91 for all subscales except for genital–urinary, which had an alpha of .46. One potential reason for the lowered alpha on the genital-urinary subscale was that there were fewer items on the subscale (n = 7).

The scale developers also established content validity using three sources. First, symptoms included on the HTSC were generated using the research team's clinical expertise in a comprehensive review of the cardiovascular and transplant literature. Second, each symptom on the tool has been endorsed by patients for a relevant time period (transplant symptoms after operation, for example), indicating that the symptoms are relevant for the heart transplant population. Finally, no completely new symptoms were written in by patients in response to the open-ended question at the end of the scale, demonstrating that the HTSC adequately represented

the wide array of symptoms experienced by heart transplant patients. Some patients wrote in symptoms in the open-ended portion of the tool, but these symptoms were simply another way to describe an item that was already included on the HTSC. Construct validity was also adequate, as demonstrated by a contrasted-groups approach comparing working and non-working heart transplant patients (n=260). Heart transplant candidates that were not working due to their health had significantly more overall symptom distress (p = .002) and more distress from cardiopulmonary symptoms (p = .003) than those who were working. Additionally, there was a significant correlation between greater symptom distress and worse disability (n = 260), as measured by the Sickness Impact Profile (SIP) (r = .52, p = .0001).

Heart Transplant Stressor Scale (HTSS; Jalowiec, Grady, & Grusk, 1988). This 81-item tool assesses the stressfulness of factors related to heart failure and heart transplant. Items were selected for this tool based on literature review and clinical expertise of the research team nurses. Patients indicate whether they have had a particular stressor in the past 6 months, and, if so, rate the stressfulness of each factor on a scale of 0-3 (0 = *not stressful at all*, 1 = *slightly stressful*, 2 = *fairly stressful*, and 3 = *very stressful*). The tool has six subscales of stressors: physical, hospital/clinic, self-care, family, work/financial, and psychological.

The HTSS was found to have sufficient psychometric support through various assessments. Cronbach's alpha (n = 175) for the total scale was .95 and ranged from .78 to .90 for the six subscales (Jalowiec, Grady, & White-Williams, 1994). Three-month test-retest reliability (n = 155) was evaluated and found to be adequate for the total scale (r = .73, p = .0001) and each subscale, with subscale correlations ranging from .51 to .72 (p = .0001 for each subscale). The scale developers also assessed for construct validity through a contrasted groups approach. Certain expected groups scored significantly higher on the hospital subscale of the

32

HTSS, including hospitalized patients ($t(43) = 7.76$, $p = .000$) and patients classified as UNOS status 1 ($t(25) = 5.93$, $p = .000$). Additionally, various groups of patients that could be expected to be sicker scored higher on the physical stressors subscale, including hospitalized patients ($t(55) = 4.05$, $p = .000$), UNOS status 1 patients ($t(29) = 2.63$, $p = .013$) and patients unemployed because of their illness ($t(35) = 3.11$, $p = .004$).

There was adequate support for criterion-related validity (n = 175) through a significant correlation between total score on the transplant-related stressors and a 10-point rating scale of overall stress due to all sources of stress ($r = .42$, $p = .000$). Lastly, predictive validity was established (n = 175) through a significant correlation between higher stressors scores and less life satisfaction ($r = -.54$, $p = .000$) as measured by the Ferrans Quality of Life Index (Ferrans & Powers, 1985), as well as a correlation between higher stressor scores and lower quality of life measured by a 10-point rating question ($r = -.38$, $p = .000$).

Cardiac Depression Scale (CDS; Hare & Davis, 1996). The CDS assesses symptoms of depression relevant to cardiac patients, including sleep disturbances, anhedonia (loss of pleasure), uncertainty, decreased mood, concentration difficulty, hopelessness, and inactivity (Hare & Davis, 1996). The CDS is sensitive to mild and moderate levels of depression, which is appropriate for cardiac patients and heart transplant recipients, for whom depression may be clinically significant even if it does not meet the criteria for a major depressive episode. This tool consists of 26 items that are rated on a 7-point scale. A higher score indicates a greater level of depression. The CDS has been shown to correlate significantly with Geriatric Depression Scale-Short Form ($r = .77$, $p = .000$) (Wise, Harris, & Carter, 2006), the Beck Depression Inventory ($r = .73$, $p < .001$), and with clinical assessment ($r = .67$, $p < .001$) (Hare & Davis, 1996). Internal consistency reliability is adequate (alpha = .90). Since the CDS was designed as a screening

measure for depression in the depressed mood range usually seen among cardiac patients, the developers suggest that a clinical cut-off score of >100 is likely to indicate more severe depression (Hare & Davis, 1996). An additional psychometric study provided more support for a CDS score of 100 to indicate more severe depression, while a score of 90 can be used to detect milder levels of depression (Wise et al., 2006).

Positive and Negative Affect Schedule—Expanded Form (PANAS– X; Watson & Clark, 1991). The PANAS–X is a 52-item scale assessing mood on two hierarchical levels (negative affect and positive affect). The PANAS-X has varying instructions that assess different time frames, but in the present study, respondents were asked to rate the extent to which they have "felt this way during the past month" using a 1–5 scale (1 = *very slightly or not at all,* 2 = *a little,* 3 = *moderately,* 4 = *quite a bit,* and 5 = *extremely).* These two mood dimensions are based on factor analyses of mood descriptors used in diverse time frames, response formats, languages, and cultures (Watson, 1988a, 1988b; Watson & Clark, 1991). The PANAS–X also assesses 11 lower order dimensions of mood, yielding subscales that reflect the specific content of different emotional states. Negative Affect, which was used in the present study, is composed of 10 items (*afraid, scared, nervous, jittery, irritable, hostile, guilty, ashamed, upset,* and *distressed).* The Negative Affect scale has some support as a trait-type construct when the general instructions are used (Watson & Clark, 1991), but the original study that created this dataset used "during the past month" instructions to capture mood states that are likely to be related to adjustment issues.

The PANAS-X has adequate psychometric support. The PANAS-X has sufficient internal consistency within the two major subscales, with Cronbach's alpha ranges from .83 to .90 for the Positive Affect scale and .84 to .91 for the Negative Affect scale (Watson & Clark, 1991). The

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reliabilities of these scales did not differ greatly when varying the time instructions used (today, past month, or past year) or type of population assessed (student, adult, or patient).

The scale developers (Watson & Clark, 1991) also demonstrated convergent validity for the PANAS-X. The Negative Affect scale has shown moderate to high correlations with other clinical measures of psychological distress, including the Beck Depression Inventory ($r = .58$; Beck, Ward, Mendelson, Mock, & Erbaugh, 1961), the State–Trait Anxiety Inventory state anxiety measure ($r = .51$; Spielberger, Gorsuch, & Lushene, 1970), and the total score of the Hopkins Symptom Checklist ($r = .74$; Derogatis, Lipman, Rickels, Uhlenhuth, & Covi, 1974). Lastly, construct validity was established through principal factor analysis. Both the Positive and Negative Affect scales were highly correlated with their corresponding regression-based factor scores in each solution, with convergent correlations ranging from .89 to .95 (samples across time frames ranged from n = 586 to n = 1,002) (Watson & Clark, 1991). Additionally, the discriminant correlations were low, ranging from -.02 to -.18, which indicates quasi-independence among these main subscales.

There is little normative data for the PANAS-X in cardiac populations. One initial study assessed various samples using a general time frame, and found that the average negative affect subscale score for a mixed clinical sample was 26.3 ($SD = 9.0$), and average score for psychiatric inpatients was 25.5 ($SD = 10.0$) (Watson & Clark, 1991). Another study with a non-clinical sample using the time frame "within the past week", average scores on the PANAS-X negative affect subscale were 16.0 ($SD = 5.9$) (Crawford & Henry, 2004). Additionally, within another initial psychometric study regarding development of the PANAS-X, the average score on the negative affect subscale in a non-clinical sample using the time frame "within the past few weeks" was 19.5 ($SD = 7.0$) (Watson, Clark, & Tellegen, 1988).

35

Jalowiec Coping Scale (JCS; Jalowiec, 2003). The JCS is a widely used tool that measures the use and effectiveness of 60 coping strategies. Patients rate their use of coping strategies (0 = *never used*, 1 = *seldom used*, 2 = *sometimes used*, 3 = *often used*) and the effectiveness of the strategies used (0 = *not helpful*, 1 = *slightly helpful*, 2 = *fairly helpful*, 3 = *very helpful*). The JCS has eight subscales: confrontive, evasive, optimistic, fatalistic, emotive, palliative, supportant, and self-reliant. These subscales can be combined into positive (confrontive, optimistic, supportant, self-reliant, positive palliation) and negative (evasive, fatalistic, emotive, negative palliation) coping strategies. Patients are instructed to rate their coping based on stresses they are experiencing at the time related to having a heart transplant.

The JCS has adequate psychometric support (Jalowiec, 2003). Various intervals of test-retest reliability were conducted across numerous studies, including three, six, nine, and twelve month intervals. The JCS demonstrated an average correlation for total use score ($r = .61$) and across the eight subscales ($r = .55$, range from .37 to .70). The scale developer explains that this moderate test-retest reliability may be due to patients' evolving coping behavior as they become more familiar with their illness rather than due to lowered reliability of the instrument.

The scale developer established content validity through the systematic manner of tool development, diverse coping behaviors included in the scale, as well as a large number of items used to adequately draw from the coping domain. To assess the construct validity of the scale, the developer evaluated the extent to which a panel of 25 nurse researchers agreed with the classification of the 60 JCS items onto the eight subscales. The panel members were given descriptions of each coping style and instructed to code each item as one of the eight styles. The average percentage of agreement between the panel's coding and the scale developer's classification of coping strategies for all eight subscales was 75%, which supported the scale

36

developer's rationally derived classification of the coping items. An additional panel of three judges were told the composition of the subscales and asked to indicate whether each item made sense on that particular subscale. The panel members had a validity index of .85, which demonstrated additional support for the subscale composition.

Lastly, the JCS has adequate concurrent and predictive validity. Greater effectiveness of coping behavior was associated with a variety of better outcomes, including more satisfaction with life ($r = .40$, $p < .001$), lower overall levels of stress ($r = -.31$, $p < .001$), better social functioning ($r = -.26$, $p < .001$), and needing less help with illness-related tasks ($r = .19$, $p = .025$). Additionally, greater use of less desirable coping behaviors was associated with poorer outcomes. For example, increased use of evasive coping was correlated with less satisfaction with life ($r = -.35$, $p < .001$) and higher overall levels of stress ($r = .48$, $p < .001$), while increased use of fatalistic coping was correlated with poorer perception of health status ($r = -.24$, $p = .005$) and more psychological symptoms ($r = .29$, $p < .001$).

Medical variables. These data were recorded either on chart review forms or on CTRD forms. The six variables that were included in this study are as follows: number of medical comorbidities, number of rejection episodes, number of infections, UNOS status at time of transplant, presence of oncology illness, and etiology of heart disease as distinguished by ischemic etiology versus all other etiologies.

Statistical Analyses

Statistical analyses were completed using PASW Statistics 18 software. In the original study prior to analyses, mean item, subscale, and total scale scores were calculated for each participant and converted to proportional scores, when indicated. Proportional scores were calculated by dividing the participant's item, subscale, or total scale score by the maximum

possible score to convert the ranges to a standard scale score with a range of .00 to 1.00. There was no calculation of proportional scores for the CDS because normative data reported by the authors of the tool used the original scale scores. For the purposes of data interpretation, variables were transformed back to their original raw value, thus providing a better understanding actual clinical differences on the various scales.

Prior to analyses in the present study, statistical assumptions within the data set were checked, including checking for missing data and assessing sample size, outliers, and normality. There are a few statistical considerations to note that take the large sample size into account for the present study. Regarding outliers, Tabachnick and Fidell (2007) note that with a large sample size, one can expect to have a few standardized scores (z-scores) greater than 3.29 (three standard deviations from the mean). Additionally, when analyzing normality, Field (2009) explains that when n>200, it is more beneficial to examine the shape of the distribution for normality, rather than skewness or kurtosis values. Three outcome variables, *satisfaction with social support, Sickness Impact Profile score*, and *Assessment of Problems with the Heart Transplant Regiment-Part A* did not have normal distributions. For *Assessment of Problems with the Heart Transplant Regiment-Part A,* a square root transformation was conducted, which resulted in a normal distribution. For *satisfaction with social support* and *Sickness Impact Profile score*, log transformations were conducted on both variables in an attempt to achieve normality. The variables were slightly kurtotic, so an additional square root transformation was conducted on each variable, which resulted in a normal distribution.

Participants were divided into two groups: older patients and younger patients. Age is generally considered a continuous variable, however much of the previously reviewed heart transplant literature uses age cut-offs to make a distinction between older and younger patients.

38

Additionally, the ISHLT and other large research organizations that publish recommendations and risk factors for transplant use age cut-offs to suggest at which age transplants become risky. Age 65 at time of follow-up was chosen as the age cut-off for defining older and younger patients, since this age cut-off is often used in research and a generally socially accepted distinction between older and younger adults. Participants who were at least age 60 at their date of transplant (at least age 65 at the 5-year follow-up) were classified as *older patients*, and all patients under age 60 at time of transplant classified as *younger patients*.

Given that the focus of this study was to examine age differences specifically and the a priori hypotheses predicted differences between older and younger adults, analyses for the age variable included a series of separate independent samples t-tests for each of the dependent variables. Results were adjusted with a Bonferroni correction, such that the level of significance was set at 0.005 for the separate t-tests. Age group was entered into analyses as an independent variable, and the outcome variable of interest (satisfaction with quality of life, negative affect, satisfaction with social support, etc.) was entered as the dependent variable. Scatter plots were also included for each analysis, demonstrating the spread of the data across patients by age group and outcome variable. Effect size was also calculated in these analyses, since even small effects may be noteworthy in the context of heart transplant outcomes, given the relatively minimal distinction of an age cut-off and the potentially important implications of the findings (Prentice & Miller, 1992). Lastly, the sample population was also evaluated with regards to normative data for depression. Since the CDS has a clinical cut-off value for depressive scores, a chi-square analysis was conducted to assess age differences in participants above and below the clinical cut-off.

The purpose of conducting these analyses with age as a categorical variable and comparing group means was to be able to answer the research question with a certain degree of external validity. Since published guidelines for organ transplant care and transplant centers themselves often state age recommendations, it would be meaningful and consistent with the literature to report results that demonstrate how patients above and below these cut-offs are adjusting and functioning following heart transplant. However, preliminary analyses showed that due to variations in date of transplant and number of years post-transplant that the patient returned the first questionnaire booklet, there were 24 patients who overlapped between the categorical age-group breakdown criteria. These 24 patients were under the age of 60 at the time of the transplant, therefore categorized as younger patients, but did not return their first booklet until after they reached the age of 65. Thus, they overlapped in the analyses and created a diffusion of the age variable, which could cause a threat to internal validity. Data were analyzed both with these 24 participants included and excluded, and the results from the independent samples t-tests did not change. When there was a significant difference between older and younger patients on a particular outcome variable, this effect remained significant when the 24 participants were excluded from the analyses. Therefore, they were included in the analyses and categorized as younger patients, which is appropriate considering that many of them were under the age of 65 for at least the first 5 years post-transplant and likely entered into the transplant with a "younger patient mindset."

Additionally, an analysis of covariance test (ANCOVA) was conducted for each outcome variable of interest to analyze any effects of site differences or the transplant institution from which each patient received his or her care. For each significant independent samples t-test, an ANCOVA was conducted using the same independent and dependent variables and

included the variable *institution* as a covariate. An important assumption for ANCOVA, the assumption of homogeneity of regression slopes, was also checked.

For a supplementary understanding of the primary results of interest, age was divided into three categorical groups, including younger, middle-aged, and older participants. The younger group included participants who were below age 45 at the time of the transplant (n = 90), the middle-aged group included those between the ages of 45 and 59 (n = 300), and the older group included those participants age 60 or older at the time of the transplant (n = 165). These groups were compared to each other using an analysis of variance (ANOVA) test, with post-hoc planned contrasts comparing the younger group to the middle-aged group, the younger group to the older group, and the middle-aged group to the older group.

A principal component factor analysis using a Direct Oblimin Rotation was conducted to determine if there were any composite variables that could be created from the ten outcome variables. The data were suitable for factor analysis, since sample size, normality, and correlation values were appropriate (Table 1).

Lastly in the data analysis, chi-square analyses and independent samples t-tests were conducted comparing the older and younger patients on basic demographic characteristics, including gender, race, marital status, and education. Additionally, the older and younger patients were also compared on certain clinical characteristics, including co-existing illnesses, rejection episodes, infections, presence of cancer, UNOS status at time of transplant, and etiology of heart failure. These analyses provided a better understanding of pre-transplant demographic differences and important medical differences between the older and younger patients, which helped inform the interpretation and discussion of the primary results.

41

Table 1.

Bivariate correlations of outcome variables

	Satisfaction with quality of life	Difficulty with adherence	Actual adherence	Overall functioning	Satisfaction with social support	Symptom distress	Stress related to transplant	Depression	Negative affect	Use of positive coping strategies
Satisfaction with quality of life	___	-.34**	-.34**	-.63**	-.45**	-.63**	-.54**	-.76**	-.57**	-.07*
Difficulty with adherence	-.34**	___	.62**	.29**	.27**	.36**	.38**	.36**	.28**	.22**
Actual adherence	-.34**	.62**	___	.24**	.25**	.29**	.30**	.33**	.26**	.18*
Overall functioning	-.63**	.29**	.24**	___	.29**	.69**	.60**	.69**	.49**	.14**
Satisfaction with social support	-.45**	.27**	.25**	.29**	___	.30**	.27**	.38**	.25**	.04
Symptom distress	-.63**	.36**	.29**	.69**	.30**	___	.73**	.68**	.60**	.26**
Stress related to transplant	-.54**	.38**	.30**	.60**	.27**	.73**	___	.63**	.56**	.29**
Depression	-.76**	.36**	.33**	.69**	.38**	.68**	.63**	___	.67**	.15**
Negative affect	-.57**	.28**	.26**	.49**	.25**	.60**	.56**	.67**	___	.17**
Use of positive coping strategies	-.07*	.22**	.18*	.14**	.04	.26**	.29**	.15**	.17**	___

Note. Suitability standards for factor analysis met (Kaiser-Meyer-Olkin Measure of Sampling Adequacy = .88; Bartlett's Test of Sphericity = 2714.68, *p* < .001.)
* *p*<.05 **p<.001.

Results

Demographic and Clinical Characteristics

The older and younger patients differed in a variety of demographic and clinical

characteristics (Table 2). The participants in this study were primarily male, Caucasian, married,

and with relatively high levels of education. As seen in Table 2, significantly more participants

in the older patient group had these demographic characteristics than participants in the younger

group. The older patients also had fewer rejection episodes and more prevalence of ischemic

etiology as reason for transplant compared to younger patients.

Table 2.

Demographic and clinical characteristics by age group

	Younger group (n = 390)	Older group (n = 165)	
Demographic	*M*	*M*	*p*
Gender (% Male)	74.1	88.5	**<.001**
Race (% White)	84.6	95.8	**.04**
Marital status (% Married)	75.6	86.1	**.001**
Years of education	13.8	14.5	**.021**
Age[a]	55.2	69.4	**<.001**
Years post-HT[a]	6.27	5.87	**<.001**
Clinical			
Number of co-existing illnesses	5.02	5.33	.19
Number of rejection episodes	2.38	1.85	**.004**
Number of infections	.70	.88	.086
Oncology illness (% yes)	6.4	9.7	.17
CAD (% yes)	43.1	40.6	.59
Etiology (% ischemic)	49.0	73.9	**<.001**

[a] At time of follow-up period—first completed questionnaire
Note. Independent samples t-tests were used for scale variables, and chi-square analyses were
used for categorical variables.

Age Group by Outcome Variable

When conducting the independent samples t-tests for nearly all of the dependent

variables, there was a significant Levene's statistic, indicating that the assumption of

43

homogeneity of variance was violated. Therefore, the test statistic and corresponding degrees of freedom reported were calculated with equal variances not assumed (Field, 2009). For the dependent variables *difficulty with adherence* and *depression*, the assumption of homogeneity of variances was met, therefore the test statistic and corresponding degrees of freedom reported were calculated with equal variances assumed. The results comparing age groups and the outcome variables are presented in Table 3 (two age groups; younger and older patients) and Table 4 (three age groups; younger, middle-aged, and older patients).

Table 3.

Outcome variables across two age groups

	Younger group	Older group			
	M (SD)	*M (SD)*	*t-value*	*p*	*Effect size*
Satisfaction with quality of life	*.80 (.16)*	*.87 (.12)*	5.06	**<.001**	0.47
Difficulty with adherence	*.24 (.19)*	*.16 (.17)*	-4.71	**<.001**	0.43
Actual adherence	*.12 (.10)*	*.08 (.08)*	-4.81	**<.001**	0.42
Overall functioning	*.17 (.10)*	*.15 (.10)*	-2.34	.02	0.20
Satisfaction with social support	*.09 (.13)*	*.06 (.10)*	-3.60	**<.001**	0.25
Post-HT symptom distress	*.08 (.05)*	*.07 (.04)*	-2.14	.03	0.21
Stress related to heart transplant	*.10 (.07)*	*.07 (.06)*	-4.09	**<.001**	0.45
Depression	*81.38 (25.30)*	*69.60 (23.03)*	-5.15	**<.001**	0.48
Negative affect	*.16 (.15)*	*.11 (.13)*	-3.60	**<.001**	0.35
Positive coping strategies	*.53 (.23)*	*.50 (.25)*	-3.60	.014	0.21

Note. Effect sizes calculated with *Cohen's d*. Significance values adjusted with a Bonferroni correction, such that the critical value is set to p < .005.

44

Table 4.

Outcome variables across three age groups

	Younger group M (SD)	Middle-aged group M (SD)	Older group M (SD)	F	df	p
Satisfaction with quality of life[a]	.80 (.16)	.81 (.16)	.87 (.12)	11.07	2, 309.06	**<.001**
Difficulty with adherence	.26 (.20)	.23 (.19)	.16 (.17)	11.97	2, 552	**<.001**
Actual adherence[a]	.14 (.12)	.12 (.10)	.08 (.08)	9.98	2, 234.75	**<.001**
Overall functioning	.16 (.11)	.17 (.10)	.15 (.10)	3.39	2, 552	.035
Satisfaction with social support[a]	.10 (.13)	.09 (.12)	.06 (.10)	5.94	2, 297.62	**.003**
Post-HT symptom distress[a]	.08 (.05)	.07 (.05)	.07 (.04)	2.72	2, 275.63	.068
Stress related to heart transplant[a]	.10 (.08)	.09 (.07)	.07 (.06)	8.72	2, 262.79	**<.001**
Depression	84.06 (28.65)	80.58 (24.20)	69.60 (23.03)	13.95	2, 552	**<.001**
Negative affect[a]	.20 (.17)	.15 (.14)	.11 (.13)	9.80	2, 259.7	**<.001**
Positive coping strategies[a]	.56 (.24)	.55 (.23)	.50 (.25)	3.21	2, 338.88	.042

[a]Homogeneity of variance assumption was not met, therefore Brown-Forsythe *F* statistical test was used. According to Field (2009), the Brown- Forsythe *F*-ratio is a robust alternative *F*-ratio that weighs the group variance by the inverse of their sample sizes to reduce the impact of large sample sizes with large variance.
Note. Significance values adjusted with a Bonferroni correction, such that the critical value is set to p < .005.

45

Overall quality of life. On the *Quality of Life Index*, where higher values indicate more satisfaction with quality of life, older patients were more satisfied with their overall quality of life ($M = .87$, $SD = .12$) than younger patients ($M = .80$, $SD = .16$), $t(380.22) = 5.06$, $p < .001$, $d = 0.47$, 95% CI [0.28, 0.65] (Figure 2). This significant difference represents approximately a medium effect size. When the variable was transformed back to its raw data form, with values ranging from 1 to 6, the older patients' average satisfaction with quality of life was 5.3, while the younger patients' average satisfaction with quality of life was a 5.0. When *institution* was included in an additional analysis as a covariate, it was not significantly related to satisfaction with quality of life, $F(1, 552) = .12$, $p = .727$. Additionally, the effect of age group on satisfaction with quality of life remained significant after controlling for institution, $F(1, 552) = 21.31$, $p < .001$.
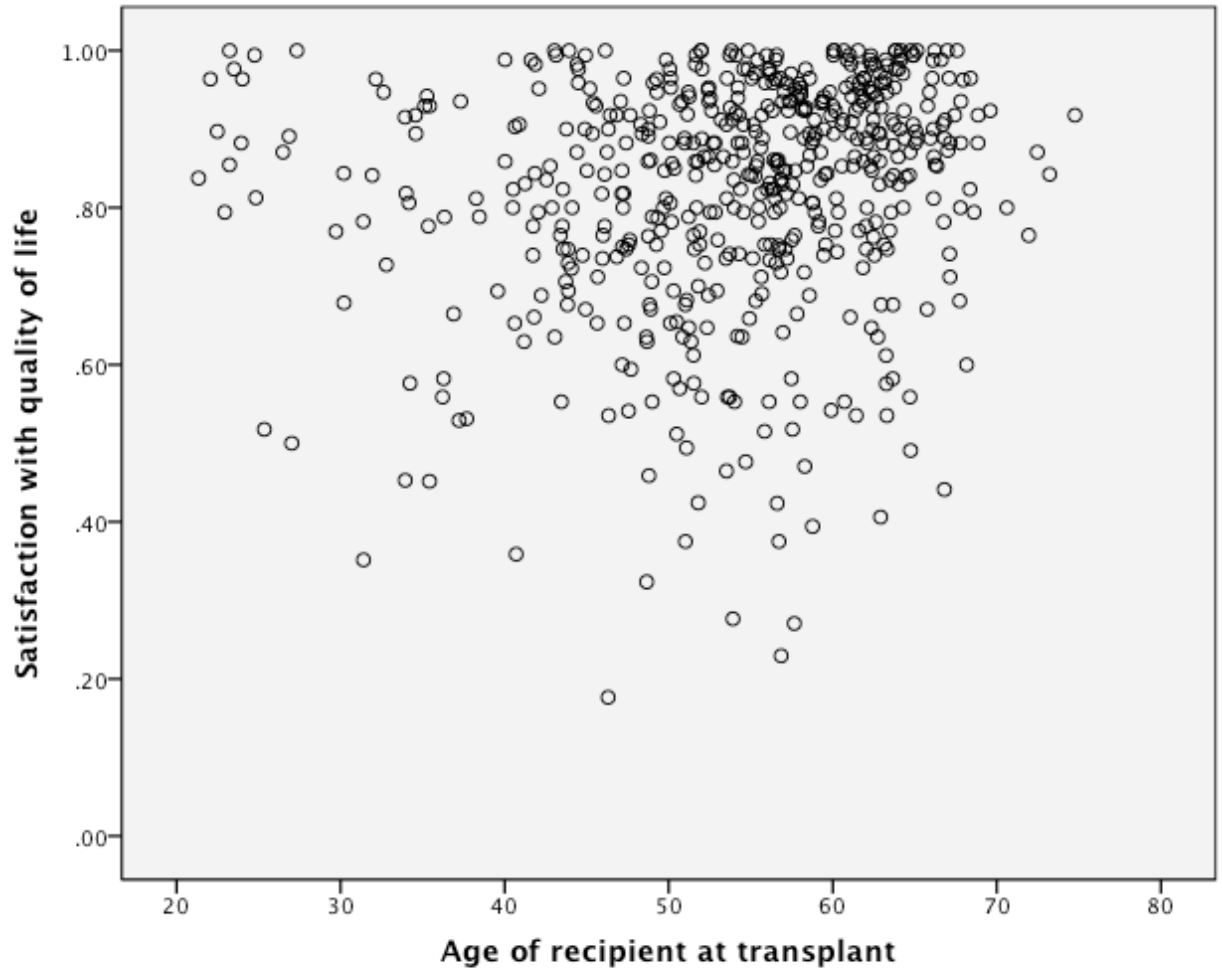
Figure 2. Scatter plot of scores on *Quality of Life Index* by patient age at time of transplant, where higher scores indicate greater satisfaction with quality of life.

A three-group comparison of younger, middle-aged, and older patients revealed that there was a significant effect of age on satisfaction with quality of life, $F(2, 309.06) = 11.07$, $p <$ .001 (Table 4). Planned contrasts revealed that the younger group scored significantly lower on satisfaction with quality life than the older group, $t(151.86) = 3.66$, $p <.001$. The middle-aged group also scored significantly lower than the older group on satisfaction with quality of life, $t(401.99) = 4.64$, $p <.001$. There was no significant difference between younger and middle-aged patients on satisfaction with quality of life, $t(145.76) = 0.46$, $p = .65$.

47

Difficulty with adherence. On the *Assessment of Problems with the Heart Transplant Regimen- Part A* scale, where higher values indicate more difficulty with adherence, older patients reported less difficulty with adherence ($M = .16$, $SD = .17$) than younger patients ($M = .24$, $SD = .19$), $t(553) = -4.71$, $p < .001$, $d = 0.43$, 95% CI [0.27, 0.64] (Figure 3). This significant difference represents approximately a medium effect size. When the variable was transformed back to its raw data form, with values ranging from 1 to 4, (1 = no difficulty, 2 = a little difficulty, 3 = moderate difficulty, 4 = a lot of difficulty), the older patients' average difficulty with adherence was 1.17 and the younger patients' average difficulty with adherence was 1.28. When *institution* was included in an additional analysis as a covariate, it was not significantly related to difficulty with adherence, $F(1, 552) = 3.403$, $p = .07$. Additionally, the effect of age group on difficulty with adherence remained significant after controlling for institution, $F(1, 552) = 21.48$, $p < .001$.
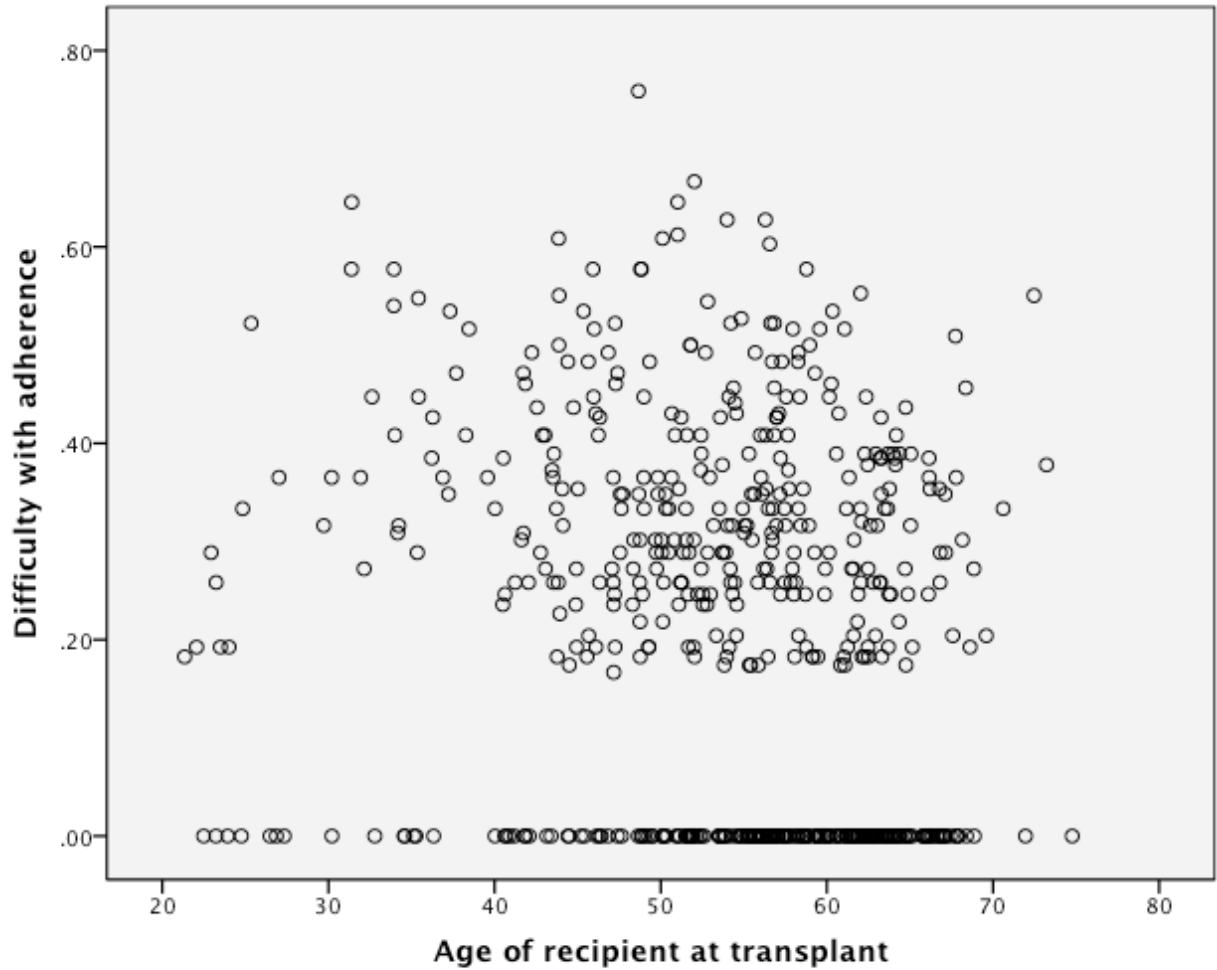
Figure 3. Scatter plot of scores on *Assessment of Problems with the Heart Transplant Regimen-Part A* by patient age at time of transplant, where higher scores indicate more difficulty with adherence.

A three-group comparison of younger, middle-aged, and older patients revealed that there was a significant effect of age on difficulty with adherence, $F(2, 552) = 11.97$, $p < .001$ (Table 4). Planned contrasts revealed that the younger group had significantly more difficulty with adherence than the older group, $t(552) = -4.26$, $p < .001$. The middle-aged group also had more difficulty with adherence than the older group, $t(552) = -4.15$, $p < .001$. There was no significant difference between younger and middle-aged patients on difficulty with adherence, $t(552) = -1.30$, $p = .19$.

49

Actual adherence. On the *Assessment of Problems with the Heart Transplant Regimen-Part B* scale, where higher values indicate more nonadherence, older patients reported less nonadherence (*M* = .08, *SD* = .08) than younger patients (*M* = .12, *SD* = .10), $t(397.70)$ = -4.81, $p < .001$, $d = 0.42$, 95% CI [0.24, 0.61] (Figure 4). This significant difference represents approximately a medium effect size. When the variable was transformed back to its raw data form, with values ranging from 1 to 4, (1 = all of the time, 2 = most of the time, 3 = some of the time, 4 = hardly ever), the older patients' average adherence was 1.25 and the younger patients' average adherence was 1.36. When *institution* was included in an additional analysis as a covariate, it was significantly related to adherence, $F(1, 552) = 9.72$, $p = .002$. Further analyses examining main effects at each institution revealed that there were significant differences in adherence between age groups at two of the sites (Cleveland Clinic Foundation; $t(182.36)$ = -3.30, $p = .001$, University of Alabama Medical Center; $t(82.95) = -2.72$, $p = .008$), and nonsignificant differences at the other two sites (Rush-Presbyterian-St. Luke's Medical Center; $t(31) = -.98$, $p = .34$, University of California, Los Angeles; $t(147) = -1.85$, $p = .07$. However, the overall effect of age group on adherence remained significant after controlling for institution, $F(1, 552) = 17.81$, $p < .001$.

Figure 4. Scatter plot of scores on *Assessment of Problems with the Heart Transplant Regimen-Part B* by patient age at time of transplant, where higher scores indicate greater nonadherence.

A three-group comparison of younger, middle-aged, and older patients revealed that there was a significant effect of age on actual adherence, $F(2, 234.75) = 9.98$, $p < .001$ (Table 4). Planned contrasts revealed that the younger group had significantly higher rates of nonadherence than the older group, $t(131.43) = -3.95$, $p < .001$. The middle-aged group also had higher rates of nonadherence than the older group, $t(397.12) = -4.06$, $p < .001$. There was no significant difference between younger and middle-aged patients on rates of nonadherence, $t(124.96) = -1.60$, $p = .11$.

51

Overall functioning. On the *Sickness Impact Profile*, where higher values indicate greater disability or limitations in functioning, older patients reported slightly less disability (*M* = .15, *SD* = .10) than younger patients (*M* = .17, *SD* = .10), *t*(332.43) = -2.34, *p* = .02, *d* = 0.20, 95% CI [0.02, 0.38] (Figure 5). This difference was not statistically significant after adjusting the significance value to 0.005 using a Bonferroni correction. When the variable was transformed back to its raw data form, older patients' average score on the SIP was 76.9 and the younger patients' average score was 99.3. The maximum score on the *Sickness Impact Profile* (SIP) is 993.7, which combines the weighted scores of the 136 items. SIP scores are interpreted by calculating a percentage of the sum of the weights of the affirmatively checked statements divided by the sum of all factor weights under analysis. Converting these scores to the scoring format used to compare clinical norms, the older patient's average score was 7.7, and the younger patient's average score was 9.9.
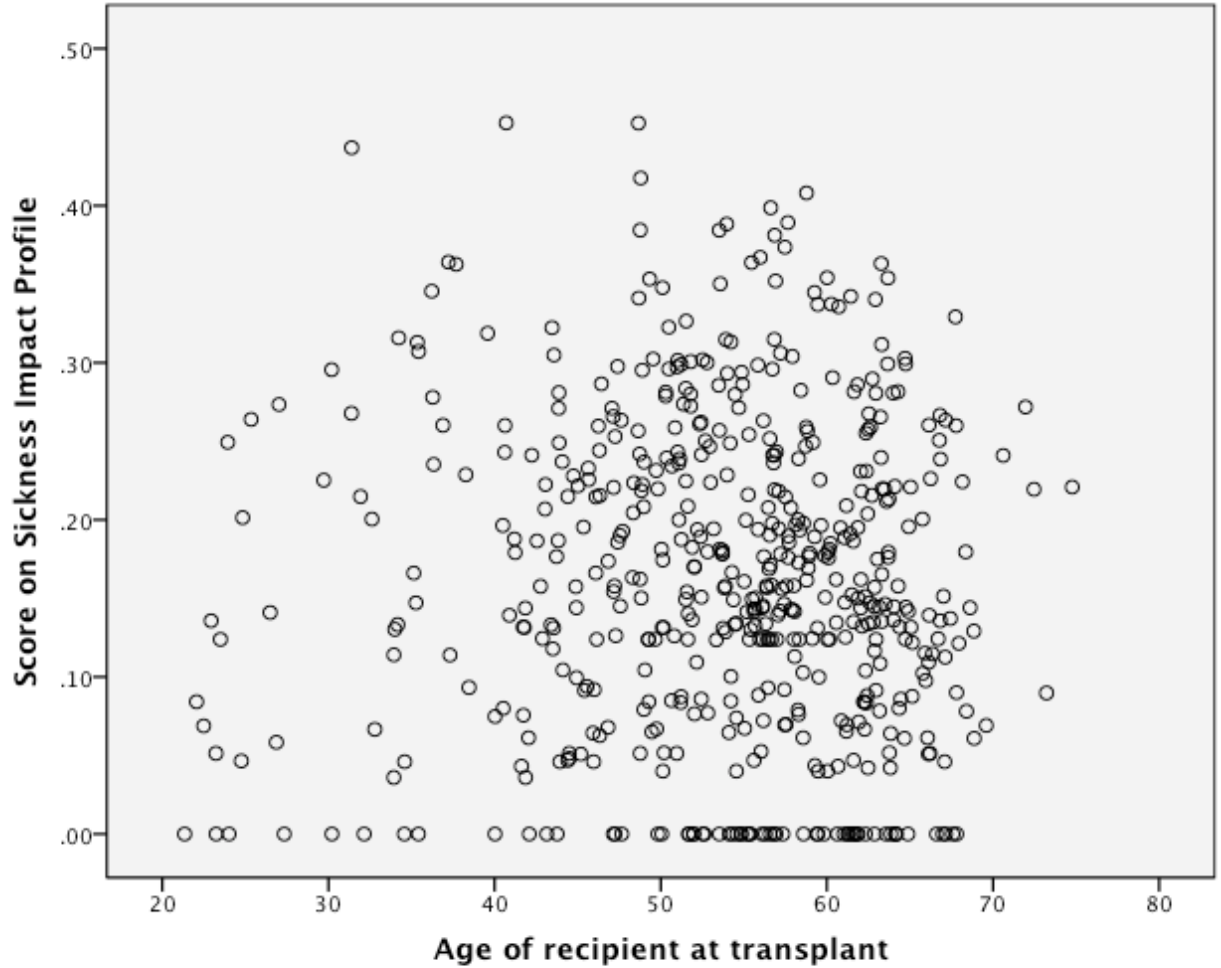
Figure 5. Scatter plot of scores on *Sickness Impact Profile* by patient age at time of transplant, where higher scores indicate more disability or dysfunction.

A three-group comparison of younger, middle-aged, and older patients revealed that there was not a significant effect of age on overall functioning, $F(2, 552) = 3.39$, $p = .035$ (Table 4). Planned contrasts revealed that the middle-aged group had significantly poorer functioning compared to the older group, $t(552) = -2.54$, $p = .011$. There were no significant differences in functioning between the younger and older age groups, $t(552) = -.70$, $p = .482$, or between the younger and middle-aged groups, $t(552) = 1.28$, $p = .20$.

53

Satisfaction with social support. On the *Social Support Index*, where higher values indicate greater dissatisfaction with social support, older patients reported less dissatisfaction with social support ($M = .06$, $SD = .10$) than younger patients ($M = .09$, $SD = .13$), $t(385.10) = -3.60$, $p < .001$, $d = 0.25$, 95% CI [0.06, 0.43] (Figure 6). This significant difference represents a small effect size. When the variable was transformed back to its raw data form, with values ranging from 1 to 4, (1 = very satisfied, 2 = fairly satisfied, 3 = somewhat dissatisfied, 4 = very dissatisfied), the older patients' average satisfaction with social support was 1.10 and the younger patients' average satisfaction with social support was 1.20. When *institution* was included in an additional analysis as a covariate, it was not significantly related to satisfaction with social support, $F(1, 552) = .18$, $p = .67$. Additionally, the effect of age group on difficulty with adherence remained significant after controlling for institution, $F(1, 552) = 10.85$, $p = .001$.
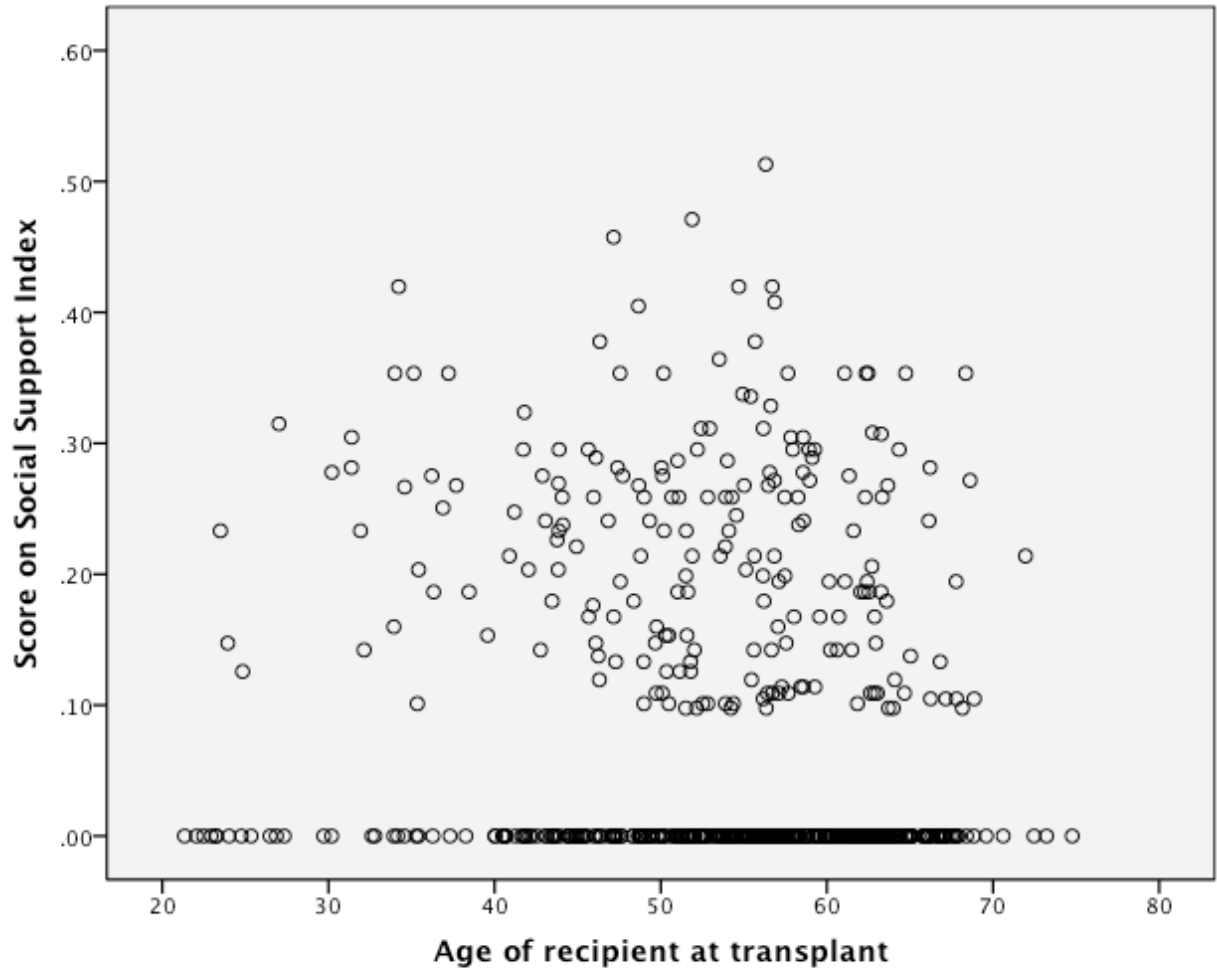
Figure 6. Scatter plot of scores on *Social Support Index* by patient age at time of transplant, where higher scores indicate greater dissatisfaction with social support.

A three-group comparison of younger, middle-aged, and older patients revealed that there was a significant effect of age on satisfaction with social support, $F(2, 297.62) = 5.94, p = .003$ (Table 4). Planned contrasts revealed that the younger group had significantly lower satisfaction with social support than the older group, $t(148.08) = -3.04, p = .003$. The middle-aged group also had lower satisfaction with social support than the older group, $t(403.66) = -3.09, p = .002$. There was no significant difference between younger and middle-aged patients on satisfaction with social support, $t(142.70) = -.97, p = .335$.

55

Post-transplant symptom distress. On the *Heart Transplant Symptom Checklist,* where higher values indicate greater post-transplant symptom distress, older patients reported less symptom distress ($M = .07$, $SD = .04$) than younger patients ($M = .08$, $SD = .05$), $t(352.67) = -2.14$, $p = .03$, $d = 0.21$, 95% CI [0.03, 0.39] (Figure 7). This difference was not statistically significant after adjusting the significance value to 0.005 using a Bonferroni correction. When the variable was transformed back to its raw data form, with values ranging from 0 to 3, (0 = not bothered at all, 1 = slightly bothered, 2 = moderately bothered, 3 = very bothered), the older patients' average symptom distress score was 0.20 and the younger patients' average symptom distress score was 0.22.
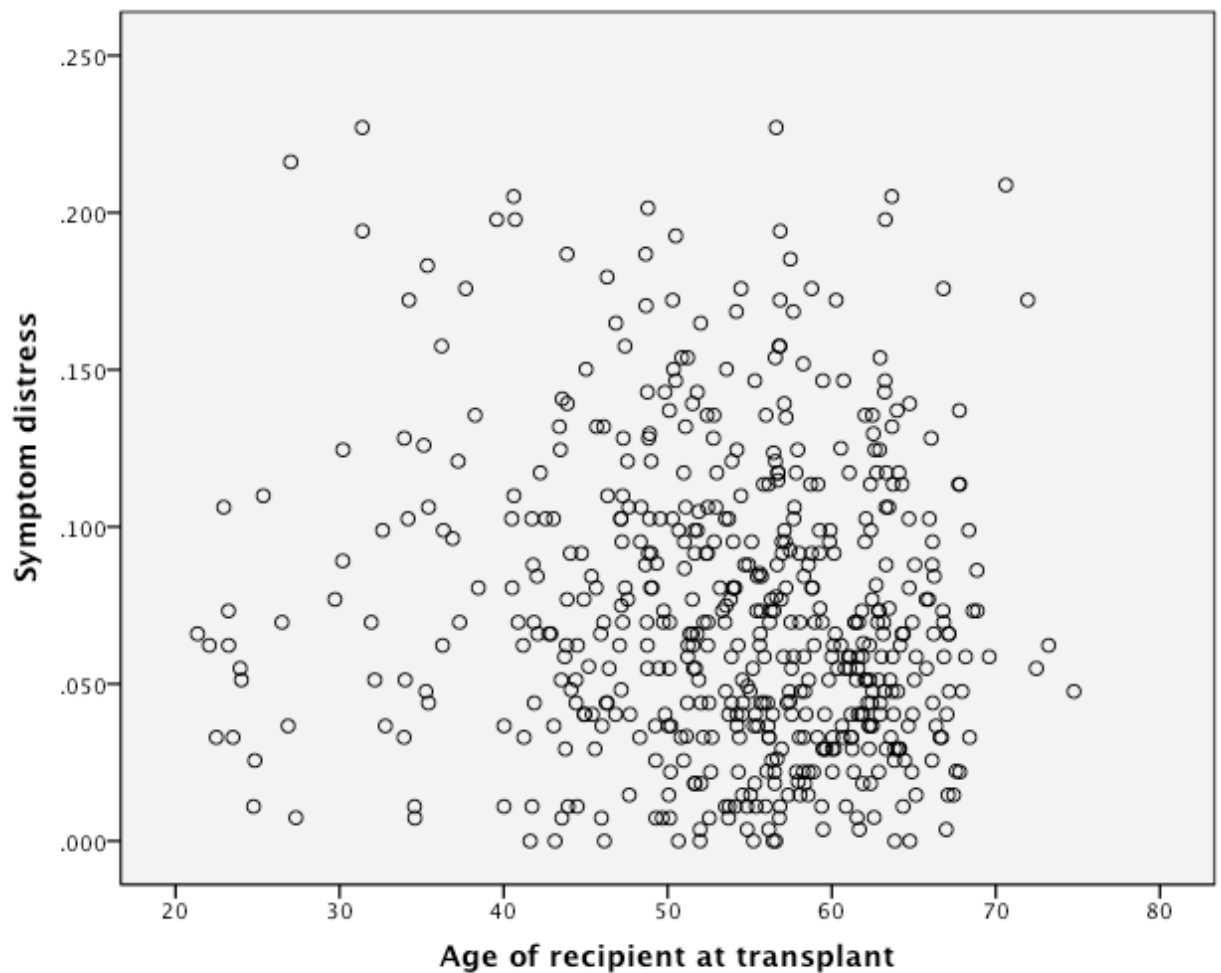
Figure 7. Scatter plot of scores on *Heart Transplant Symptom Checklist* by patient age at time of transplant, where higher scores indicate greater distress from symptoms related to the heart transplant.

A three-group comparison of younger, middle-aged, and older patients revealed that there was not a significant effect of age on post-transplant symptom distress, $F(2, 275.63) =$ 2.72, $p = .068$ (Table 4). Planned contrasts revealed that the younger group had more post-transplant symptom distress than the older group, $t(149.04) = -2.21$, p $= .029$, however this difference was not significant after a Bonferroni correction adjusting the significance value to p <.016. There were no significant differences between younger and middle-aged patients, $t(131.46) = -1.18$, $p = .24$, nor the middle-aged and older patients on post-transplant symptom distress, $t(368.20) = -1.66$, $p = .10$.

Stress related to heart transplant. On the *Heart Transplant Stressor Scale,* where higher values indicate greater post-transplant stress, older patients reported experiencing less stress ($M = .07$, $SD = .06$) than younger patients ($M = .10$, $SD = .07$), $t(352.66) = -4.09$, $p < .001$, $d = 0.45$, 95% CI [0.26, 0.63] (Figure 8). This significant difference represents approximately a medium effect size. When the variable was transformed back to its raw data form, with values ranging from 0 to 3, (0 = not stressful at all, 1 = slightly stressful, 2 = fairly stressful, 3 = very stressful), the older patients' average stress level was 0.16 and the younger patients' average stress level was 0.22. When *institution* was included in an additional analysis as a covariate, it was not significantly related to post-transplant stress, $F(1, 552) = 2.36$, $p = .125$. Additionally, the effect of age group on stress remained significant after controlling for institution, $F(1, 552) =$ 14.38, $p < .001$.
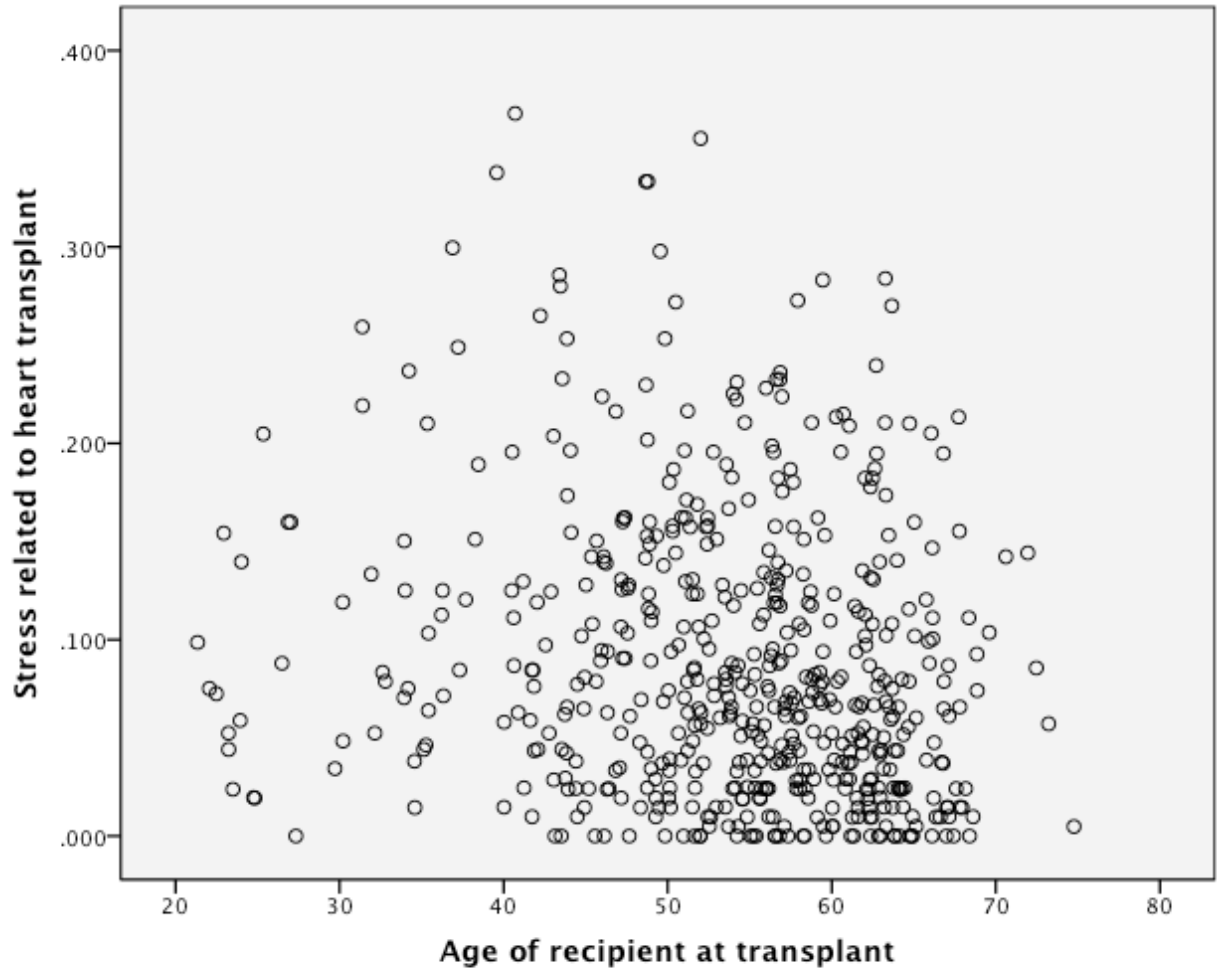
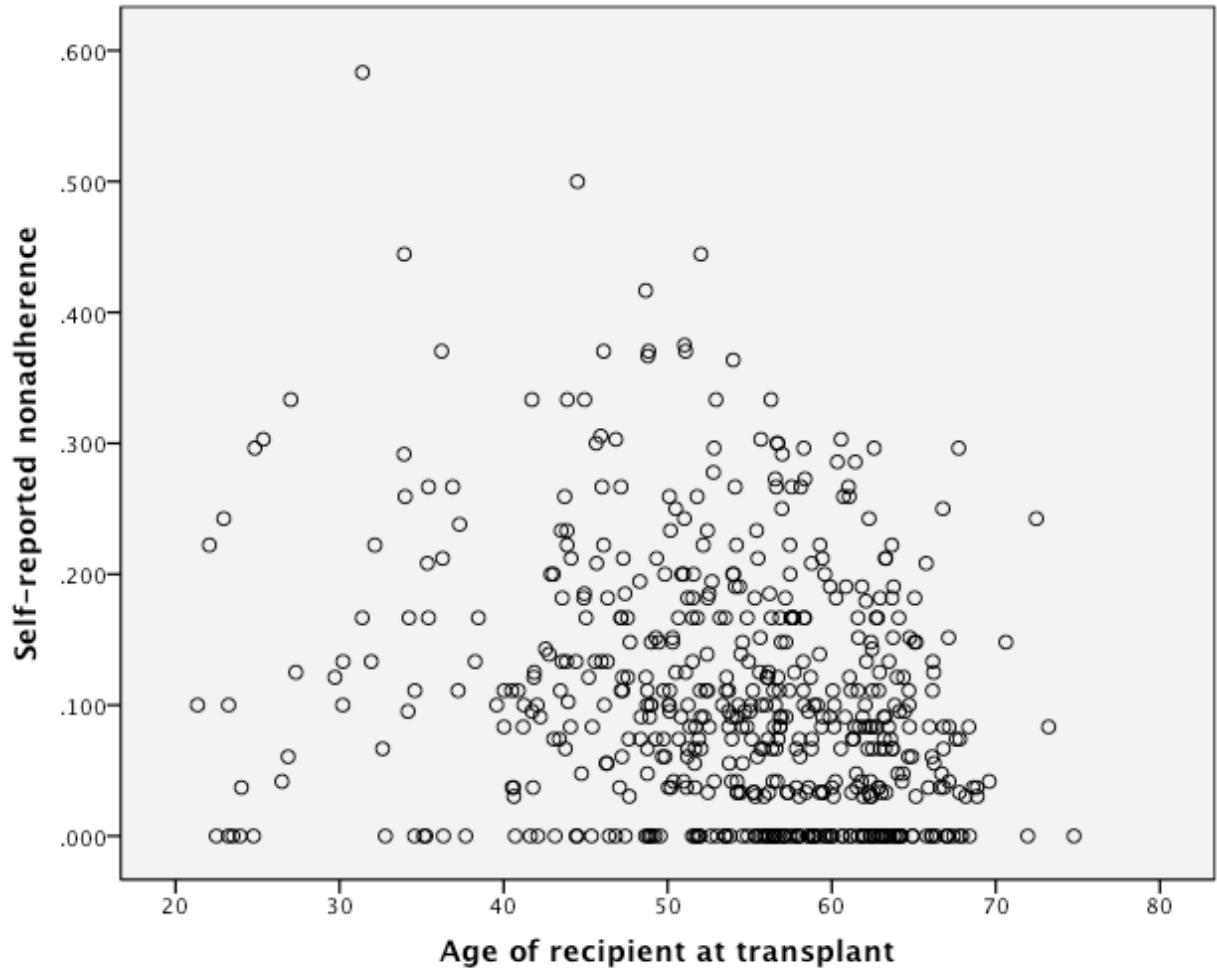*Figure 8.* Scatter plot of scores on *Heart Transplant Stressor Scale* by patient age at time of transplant, where higher scores indicate greater stress related to the heart transplant.

A three-group comparison of younger, middle-aged, and older patients revealed that there was a significant effect of age on stress related to the heart transplant, $F(2, 262.79) = 8.72$, $p < .001$ (Table 4). Planned contrasts revealed that the younger group had significantly more heart transplant related stress than the older group, $t(145.81) = -3.83$, $p < .001$. The middle-aged group also had more heart transplant related stress than the older group, $t(363.31) = -3.33$, $p = .001$. There was no significant difference between younger and middle-aged patients on stress related to the heart transplant, $t(127.64) = -1.81$, $p = .07$.

58

Depression. On the *Cardiac Depression Scale*, where higher values indicate more depression, older patients reported less depression ($M = 69.6$, $SD = 23.03$) than younger patients ($M = 81.38$, $SD = 25.30$), $t(553) = -5.15$, $p < .001$, $d = 0.48$, 95% CI [0.29, 0.66] (Figure 9). This significant difference represents approximately a medium effect size. There were additional age group differences in regards to clinical levels of depression. Younger patients scored above the clinical threshold significantly more often than older patients, $\chi^2 (1) = 7.07$, $p = .008$, OR = 2.03[1] (Figure 10). When *institution* was included in an additional analysis as a covariate, it was not significantly related to depression, $F(1, 552) = .001$, $p = .974$. Additionally, the effect of age group on depression remained significant after controlling for institution, $F(1, 552) = 26.38$, $p < .001$.

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[1] Field (2009) suggests calculating an odds ratio in chi-square analyses, rather than Cramer's V statistic, since odds ratio is a more commonly used and useful measure of effect size for categorical data. The odds ratio was calculated by dividing the odds of younger patients having clinically significant levels of depression by the odds of older patients having clinically significant levels of depression.
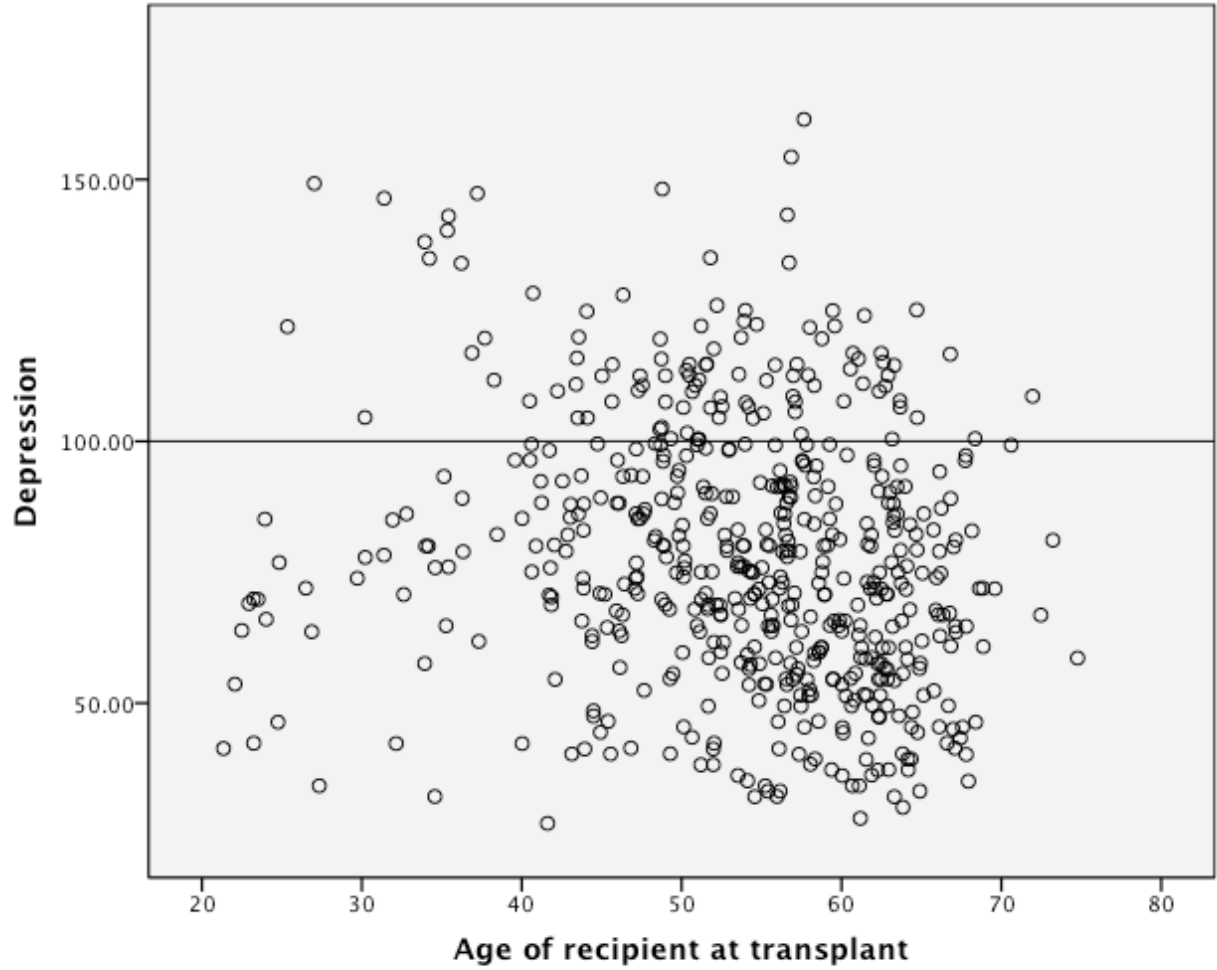
Figure 9. Scatter plot of scores on *Cardiac Depression Scale* by patient age at time of transplant, where higher scores indicate greater depression. The horizontal line on the y-axis signifies the clinical cut-off value indicative of more severe depression.
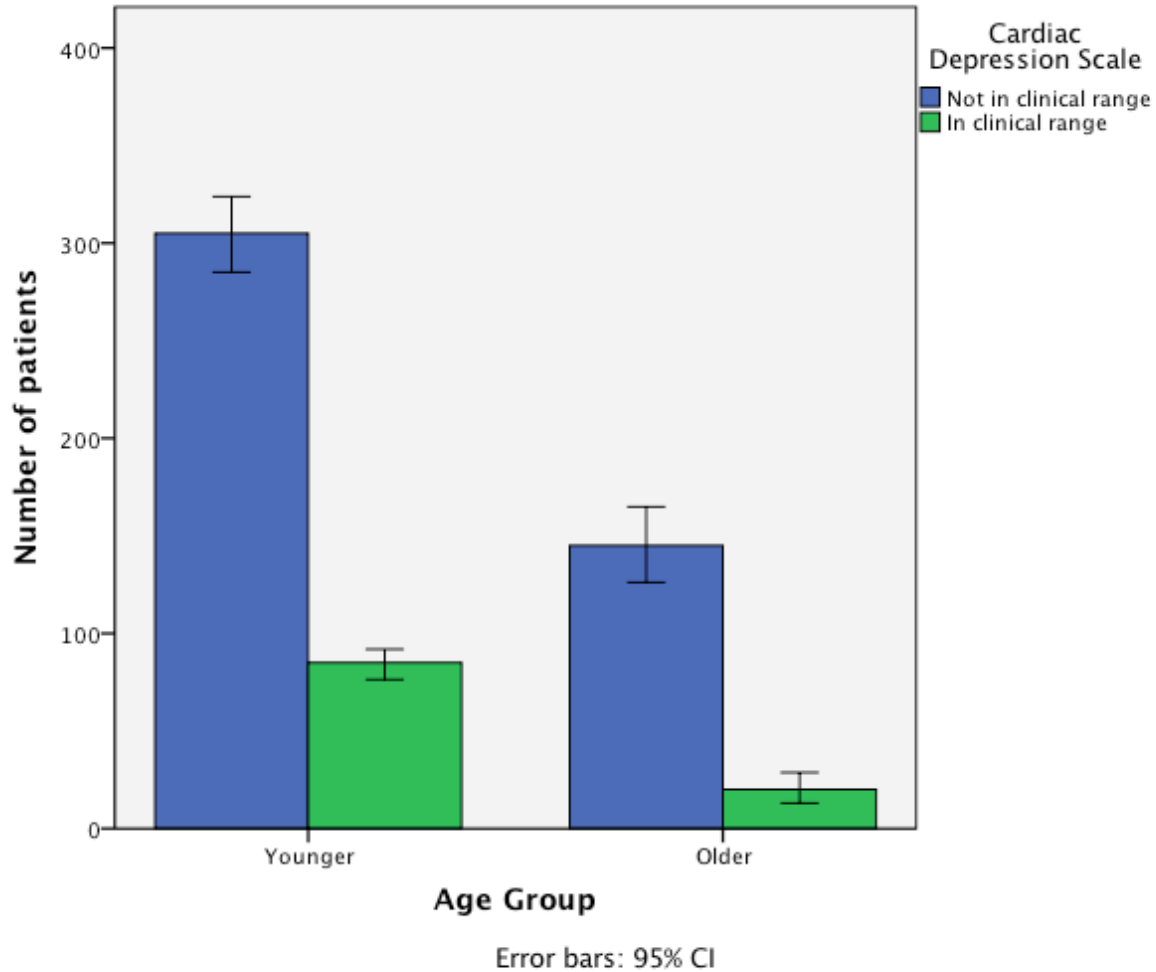
Figure 10. Bar chart of scores on *Cardiac Depression Scale* by age group and frequency of patients scoring within the clinical range.

A three-group comparison of younger, middle-aged, and older patients revealed that there was a significant effect of age on depression, $F(2, 552) = 13.95$, $p < .001$ (Table 4). Planned contrasts revealed that the younger group had significantly higher depression scores than the older group, $t(552) = -4.48$, $p < .001$. The middle-aged group also had higher depression scores than the older group, $t(552) = -4.60$, $p < .001$. There was no significant difference between younger and middle-aged patients on depression scores, $t(552) = -1.18$, $p = .24$.

61

Negative affect. On the *Positive and Negative Affect Schedule-Expanded Form,* where higher values on the negative affect subscale indicate increased frequency of experiencing negative affect, older patients reported less negative affect (*M* = .11, *SD* = .13) than younger patients (*M* = .16, *SD* = .15), $t(355.67) = -3.60$, $p < .001$, $d = 0.35$,95% CI [0.16, 0.53] (Figure 11). This significant difference represents a small to medium effect size. When the variable was transformed back to its raw data form, with values ranging from 1 to 5 as participants rate the extent to which they have "felt this way during the past month" (1 = *very slightly or not at all,* 2 = *a little,* 3 = *moderately,* 4 = *quite a bit,* and 5 = *extremely*) the older patients' average negative affect was 1.44 and the younger patients' average negative affect was 1.63. After converting these scores to total subscale scores that can be compared with known normative data, the older patients' average score on the negative affect subscale was 14.4, and the younger patients' average score was 16.3. When *institution* was included in an additional analysis as a covariate, it was not significantly related to negative affect, $F(1, 550) = .002$, $p = .965$. Additionally, the effect of age group on negative affect remained significant after controlling for institution, $F(1, 552) = 11.48$, $p = .001$.
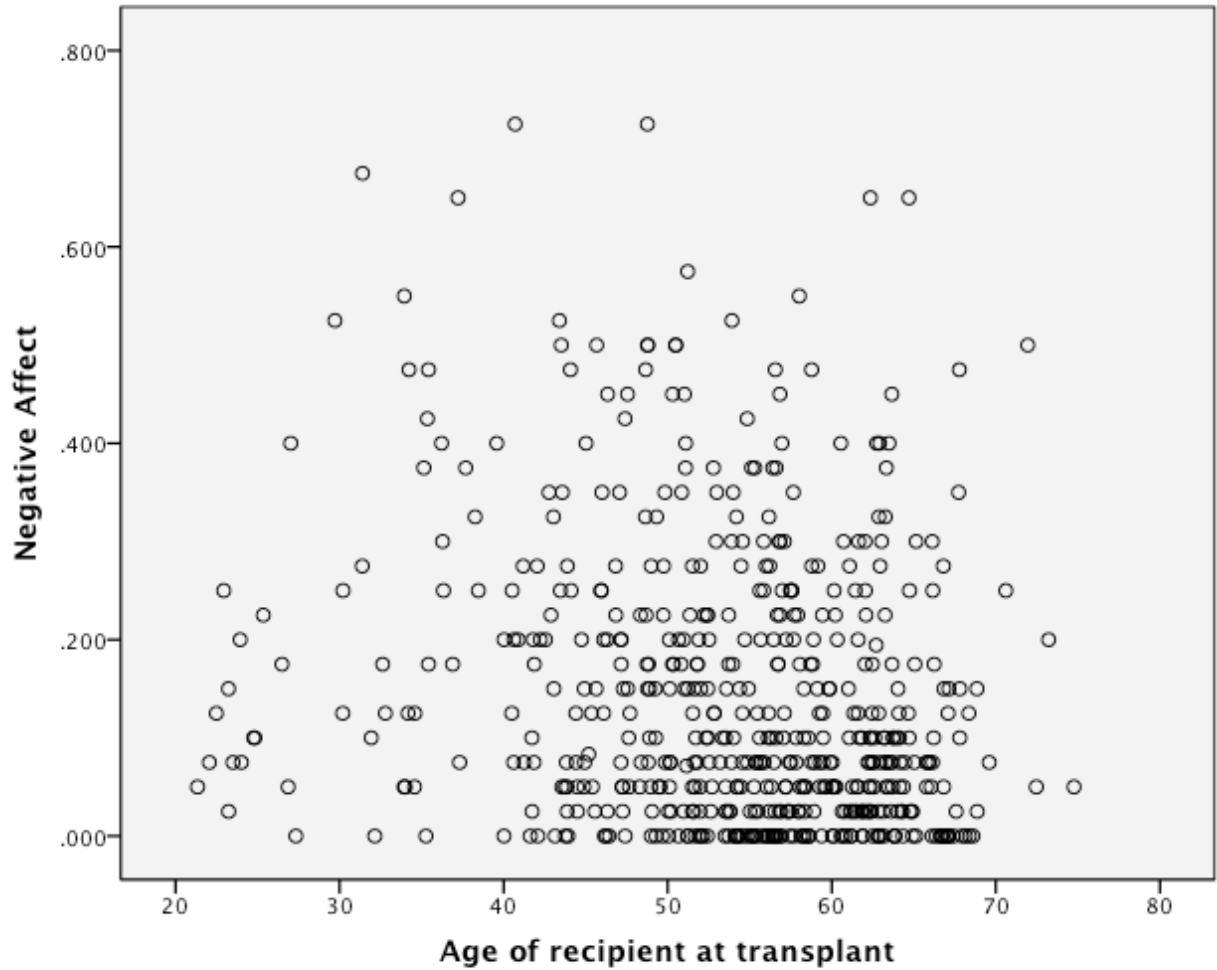
Figure 11. Scatter plot of scores on the negative affect subscale of the *Positive and Negative Affect Schedule* by patient age at time of transplant, where higher scores indicate more negative affect.

A three-group comparison of younger, middle-aged, and older patients revealed that there was a significant effect of age on degree of negative affect, $F(2, 259.7) = 9.80, p < .001$ (Table 4). Planned contrasts revealed that the younger group had significantly more negative affect than the middle-aged group, $t(126.94) = -2.76, p = .007$, and the older group, $t(144.94) = -4.22, p < .001$. The middle-aged group also had more negative affect than the older group, $t(362.65) = -2.51 p = .012$.

Positive coping strategies. On the *Jalowiec Coping Scale*, where higher values indicate more frequent use of a particular coping strategy, older patients reported less frequent use of positive coping strategies ($M = .50$, $SD = .25$) than younger patients ($M = .55$, $SD = .23$), $t(280.36) = -3.60$, $p = .014$, $d = 0.21$ (95% CI [0.15, 0.52] (Figure 12). This difference was not statistically significant after adjusting the significance value to 0.005 using a Bonferroni correction. When the variable was transformed back to its raw data form, with values ranging from 0 to 3, (0 = never used, 1 = seldom used, 2 = sometimes used, 3 = often used), the older patients' average use of positive coping strategies was 1.49 and the younger patients' average use of positive coping strategies was 1.66.
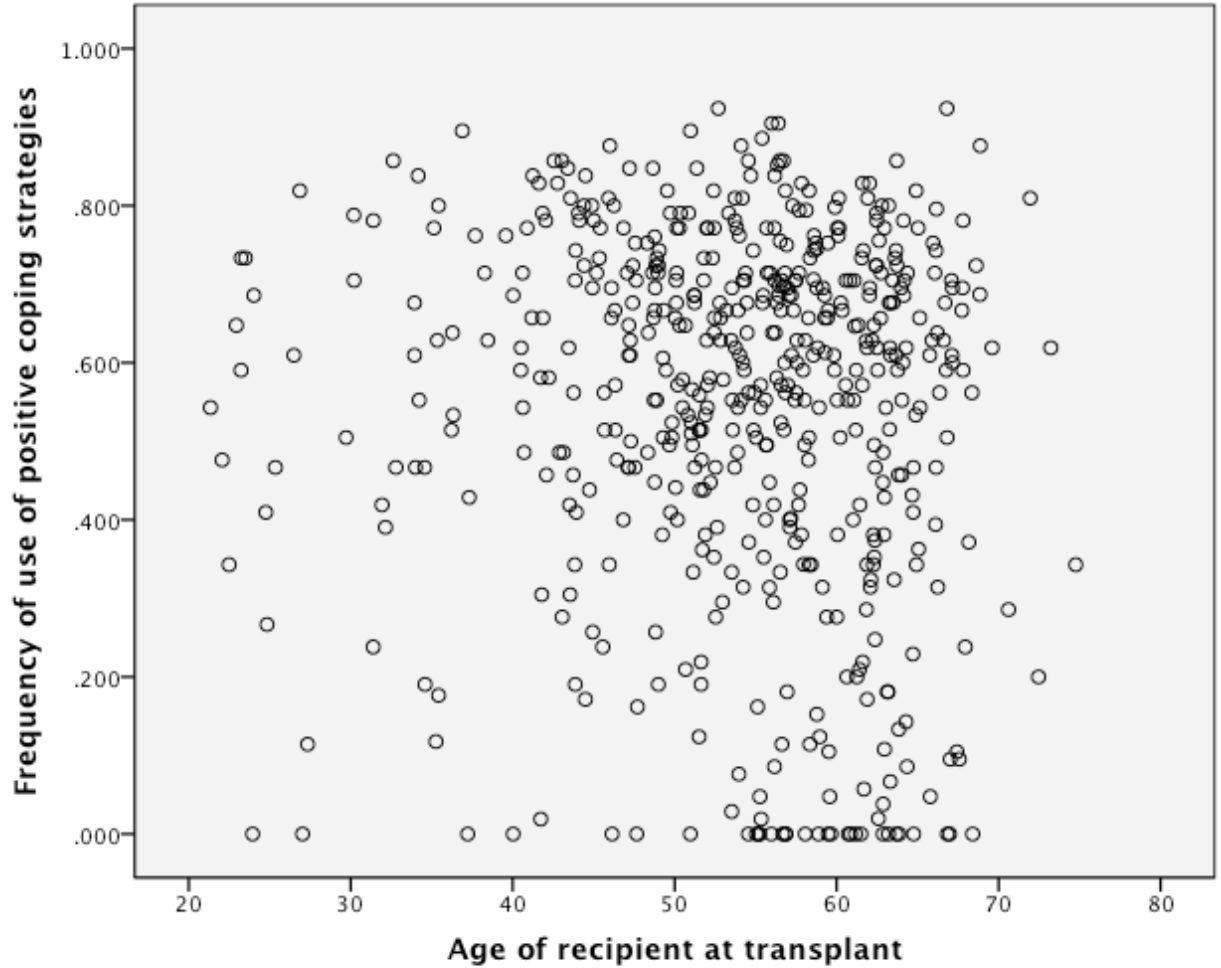
Figure 12. Scatter plot of scores on the positive coping strategies subscale of the *Jalowiec Coping Scale* by patient age at time of transplant, where higher scores indicate more frequent use of positive coping strategy.

A three-group comparison of younger, middle-aged, and older patients revealed that there was not a significant effect of age on overall functioning after adjusting using a Bonferroni correction, $F(2, 338.88) = 3.21$, $p = .04$ (Table 4). Planned contrasts revealed that there was no significant difference between younger and older patients' use of positive coping strategies, $t(192.80) = -1.84$, $p = .07$. Younger patients also did not differ in their use of positive coping strategies compared to middle-aged patients, $t(140.46) = -.09$, $p = .93$. Middle-aged patients, however, did use positive coping strategies more often than older patients, $t(304.64) = -2.37$, p

65

= .018, however this difference was not significant after the Bonferroni correction adjusting the significance value to .016.

Factor Analysis

Variables included in the factor analysis met the necessary requirements for sample size, strength of the relationship, and normality of variables. A principal component analysis was conducted with an Oblimin rotation, which found evidence for a one-factor solution based on the Eigenvalue rule and the scree tests (DeVellis, 2003). The first factor accounted for 48.22% of the variance. Variables were considered to load on this factor if (a) they loaded at or above 0.7 on the factor and (b) they did not cross-load at or above 0.3 on any other factor. The variables that loaded on this first factor were depression, post-transplant symptom distress, satisfaction with quality of life, stress related to the heart transplant, overall functioning, and negative affect. Each of these variables loaded substantially onto the factor (all loadings greater than 0.74). These variables were then combined into a composite variable. The scores on the Cardiac Depression Scale were recalculated into proportional scores between 0 and 1.00 so that all variables would be on the same scale relative to each other. Additionally, the majority of the variables that loaded onto this factor had scales where higher values indicated a generally worse outcome (more depression, more symptom distress, more stress, poorer functioning, and more negative affect), however higher scores on satisfaction with quality of life indicated a more desirable outcome (more satisfaction). Therefore, satisfaction with quality of life was reverse coded so that all variables could create a composite score where higher values signify poorer outcomes.

The composite score was created by calculating the mean of the six variables that loaded onto the first factor. On this composite score, older patients scored significantly lower (M = .17,

SD = .07) than younger patients (*M* = .20, *SD* = .08), $t(551) = -4.36$, $p < .001$, $d = 0.39$, 95% CI [0.21, 0.57]. This difference represents a small to medium effect size. Similar results were found when using the three-group comparison of younger, middle, and older adults. There was a significant effect of age group on the composite variable, $F(2, 218.70) = 10.99$, $p < .001$. Planned contrasts revealed that the younger group scored significantly higher on the composite variable than the older group, $t(145.02) = -3.80$, $p < .001$. The middle-aged group also scored significantly higher on the composite variable compared to the older group, $t(363.13) = -3.99$, $p < .001$. The younger group and middle-aged group, however, did not score significantly different on the composite variable, $t(127.12) = -1.36$, $p = .177$.

Discussion

The present study sought to reinforce the shifting mindset that older patients show at least comparable outcomes to younger patients in terms of heart transplant outcomes (Mehra et al., 2006). Given the controversial role that age plays in regards to organ allocation (Bramstedt, 2001; Tong et al., 2010), it is important for research to continue examining outcomes both in terms of survival and quality of life. Increasing life expectancy and the growing percentage of the population above age 65 will contribute to the demand for heart transplants, while it appears the supply of available hearts for transplant will remain stable. With the changing demographics of the U.S. population and improvements in technology and medicine, there have been changes in "age caps" for heart transplant patients over the last several decades (Mehra et al., 2006). Continued research is needed to assess how these changes in practice are impacting outcomes for patients in order to inform future heart transplant recommendations and guidelines.

Primary Age Differences

The array of findings in the present study point to an overall higher quality of life among heart transplant patients older than 65 relative to those under age 65. Older patients had more favorable outcomes relative to younger patients in a wide range of domains. Additionally, a relatively high degree of confidence can be placed in these findings, since the statistical analyses were adjusted using the conservative Bonferroni correction. The Bonferroni correction adjusted the critical significance value to $p < .001$, which signifies 99.9% confidence that the resultant differences are genuine and not chance findings (Field, 2009).

Overall quality of life. Older patients reported higher satisfaction with quality of life than the younger patients, which is a critical finding since one could argue that quality of life is one of the most important outcomes to examine post-transplant. There are several potential reasons for this finding. First, satisfaction with quality of life may represent an overall evaluation of adjustment that encompasses many of the other variables where age differences were also found, including mood, social support, and stress related to the heart transplant. As seen in Table 2, satisfaction with quality of life was highly correlated with these other variables. Another reason for the older patients' higher satisfaction with quality of life may be due to changes in emotion regulation that occur with age. Socioemotional selectivity theory hypothesizes that as people age, there is a motivational shift towards investing more in the quality of social relationships and an overall improved appreciation of life (Carstensen et al., 2003). There is a desire to focus on the present, derive satisfaction from life, and experience more positive than negative emotional states. Researchers have also found that older adults tend to engage in more downward social comparison as a function of emotionally regulatory goals, whereas younger adults engage in more upward social comparison as a function of self-assessment (Heckhausen & Krueger, 1993). Therefore, older patients in the present study may

have been more generally satisfied with their quality of life due to their motivations for emotional satisfaction and tendencies towards downward comparison, while the younger patients were focused on upward comparison between themselves and "superior" others (Heckhausen & Krueger, 1993).

Another important consideration in comparing older and younger patients' quality of life is that satisfaction depends on a perception of personal quality of life. A variety of research has demonstrated there may be discrepancies in how older adults perceive and characterize their quality of life compared to others' perceptions. One study found that older adults' perceptions of their health and well-being is often better than their own physicians' perceptions of the older adult's quality of life (Uhlmann & Pearlman, 1991). Another study found that more than 75% of a community sample of older adults rated themselves as aging successfully, although only 15% reported an absence of disability or physical illness (Montross et al., 2006). Thus, in the present study, the age differences in satisfaction with quality of life seem to reflect findings in other areas of literature demonstrating similar age differences in subjective perceptions of quality of life.

Adherence. Older patients also displayed less difficulty with adherence and better adherence behavior than younger patients. This is certainly an important difference to note, since post-transplant nonadherence rates are relatively high (20-50%) and can have fatal consequences for patients (Laederach-Hoffman & Bunzel, 2000). Despite known obstacles in general for older patients and medication adherence, including challenges with vision, hearing, memory, environmental and financial support (Murray et al., 2004), older patients in this study seemed to have better adherence behavior than younger patients. Similar results have been seen in previous literature in which older heart failure patients (Evangelista et al., 2001) and older

69

renal transplant patients (Gremigni et al., 2007) had better medication adherence than younger patients. In other illness domains that require similarly complex medical regimens, such as diabetes, older patients again tend to demonstrate better adherence than younger patients (Ho et al., 2006).

Adherence, like any health behavior, can be conceptualized through numerous models for understanding and predicting why certain population subgroups might be more or less adherent than others. The health belief model (Glanz, Rimer, & Lewis, 2002) might suggest that the older patients have experienced more cues to action from same-age peers that prompt better adherence behavior in general. Additionally, the older patients may have had more experience with health issues and disease management, simply as a result of having more years of life lived than the younger patients. According to the self-efficacy portion of the health belief model (Bandura, 1997), this previous experience would improve self-efficacy towards the complicated medical regimen and thus improve adherence. Alternatively, the age differences in adherence seen in the present study can be considered through the common-sense model (Hale, Treharne, & Kitas, 2007; Leventhal, Meyer, Nerenz, 1980; Meyer, Leventhal, Gutmann, 1985). Illness representation may have differed between the older and younger patients, such that the older patients viewed the heart transplant as an opportunity for improvement in quality of life, whereas the younger patients may have viewed the same transplant as a negative health event that is incongruent with general perceptions of health for their age group. Additionally, the older patients with more years of illness experience may have had more realistic expectations of the post-operative recovery period and long-term management than the younger patients. It may have also been the case that that the older and younger patients differed in their expected time-line for recovery and expected consequences of the surgery.

70

Overall, these models of health behavior may help to explain the age differences in adherence found in the present study. Given the importance of adherence in organ transplant (Collins & Labott, 2007; Olbrisch et al., 2002), the present findings add to the small body of literature demonstrating important age differences in adherence rates. Older patients appear to have relatively better adherence than younger patients, despite the previously mentioned medical regimen adherence challenges older patients face, and further exploration of this research area may be very useful for post-transplant care and future intervention development for all patients.

Social support. The older patients were also more satisfied with their social support than younger patients. This finding is particularly important, since social support is often a critical area of a patient's life that is considered in the pretransplant evaluation (Collins & Labott, 2007; Olbrisch et al., 2002). The transplant team assesses the both the quantity and quality of the patient's social support system, since poor social support is related to increases in posttransplant psychological distress (Dew et al., 1994). In the present study, the Social Support Index assessed not only the structure of social support, but also the function of the support network since patients were asked to evaluate how satisfied they were with the support received. This is an important distinction to make, since assessing function of support may be more nuanced than simply measuring the structure of a support network. Additionally, research from the literature on stress and coping demonstrates that perceived social support, or the perception that one's social network is ready to provide aide if needed, is more important than actual support received in predicting adjustment to a stressful life event (Wethington & Kessler, 1986).

The socioemotional selectivity theory can also be an explanation for why the older patients reported being more satisfied with their social support than the younger patients in the study. According to the theory, older adults often engage in antecedent emotional regulation, or

71

the process of proactively avoiding negative emotions (Carstensen et al., 2003). As such, older adults regulate their social networks and structure their social worlds to optimize the emotional meaningfulness of those relationships. Several studies have found that older adults often have smaller social networks than younger adults (Cornwell, Laumann, & Schumm, 2008; Lawton, Moss, & Fulcomer, 1987). Although older adults have smaller social networks and interact with others less often than younger adults, the social networks of older adults are made up of emotionally close social partners. Older adults' decrease in size of social networks is a result of an active pruning process of peripheral social partners, leaving a small social network of highly satisfying relationships (Carstensen et al., 2003). Thus, in the present study, the older patients may have reported significantly higher satisfaction with social support than the younger patients due to the structure and make-up of their social network even prior to the heart transplant.

Stress. Older patients also reported being less stressed by heart transplant stressors and other factors related to heart failure than the younger patients. This finding is consistent with findings from the developmental psychology literature, in which various studies have found that compared to younger adults, older adults have greater emotional control and fewer negative emotional experiences (Gross et al., 1997), report fewer stressful life events (Paykel, 1983), fewer daily hassles (Chiriboga, 1997) and experience these hassles as less stressful (Aldwin, 1990).

One reason why the older patients demonstrated better adjustment regarding stress and may be due to previous life experiences. Considering the inoculation hypothesis (Eysenck, 1983), it may be the case than the older patients experienced the transplant surgery, the complicated medical regimen, and general health-related stress as less stressful since they are more likely to have experienced similar events in the past compared to the younger patients.

This explanation has been used in previous studies of age differences in coping with health issues, including a noteworthy study completed in 1984 that examined a large group of patients (n = 758) across six different chronic illnesses (Cassileth et al., 1984). These researchers found that older patients (>60 years old) had better total mental health scores than middle-aged or younger patients in all diagnostic groups. They suggest that the older patients may have developed more effective stress management skills as a result of more years and experience with health illnesses. The researchers also note that older patients' perspectives and expectations may be more suitable for adaptation to illness than that for younger patients.

This finding may also be explained by considering both the socioemotional selectivity theory (Carstensen et al., 2003) and the buffering hypothesis. According to the buffering hypothesis, social support acts a resource that blunts the effects of stress (Cohen & Wills, 1985). Research has shown that the buffering hypothesis is best supported by studies that examine the functional rather than structural elements of social support (Taylor, 2007), as was measured in the present study by satisfaction with social support. While socioemotional selectivity theory can account for why older adults tend to have small, highly satisfying social networks, the buffering effects of social support might explain the mechanism through which the older patients in the present study reported less stress.

Depression and negative affect. Older patients also had lower levels of both negative affect and depression compared to younger patients. Compared to known normative data regarding negative affect on the *Positive and Negative Affect Schedule*, both older and younger patients reported similar levels of negative affect compared to nonclinical samples (Crawford & Henry, 2004; Watson et al., 1988), psychiatric inpatient and mixed clinical samples (Watson & Clark, 1991). This finding is important since some research has found that mood and depression

73

are important predictors for post-transplant adherence (Lisson, Rodrigue, Reed, & Nelson, 2005) and physical morbidity and mortality outcomes, including the development of cardiac allograft disease (Dew et al., 1999). Additionally, the older patients' overall less negative affect and mood may have played a role in the other adjustment and adherence outcomes found in the present study. One study examining heart transplant patients found that higher positive expectations prior to their transplant significantly predicted later adherence to the medical regimen and physical health outcomes (Leedham, Meyerowitz, Muirhead, & Frist, 1995).

The findings in the present study are consistent with previous literature, which found older patients were less depressed and reported less negative affect than younger patient populations after heart transplant (Martinelli et al., 2007) and across a variety of chronic illnesses (Cassileth et al., 1984). Given that depression and affect are presumably influenced by emotion regulation processes, the socioemotional selectivity theory again offers a plausible explanation for the current findings. Emerging out of the socioemotional selectivity theory literature, there is a growing body of evidence that finds older adults regulate their emotions in such a way that optimizes positive emotion and minimizes negative emotion (Carstensen & Mikels, 2005). This *positivity effect* has been seen in studies demonstrating that older adults prefer, attend to, and remember positive information better than negative information, both in working memory studies (Mikels, Larkin, Reuter-Lorenz, & Cartensen, 2005) and autobiographical memory (Kennedy, Mather, & Carstensen, 2004). The *positivity effect* is often examined by considering the ratio of positive to negative information recalled between older and younger adults (Charles, Mather, & Carstensen, 2003). For instance, Charles, Mather, and Carstensen (2003) found that while there was an overall decrease in image recall with age, the ratio of positive to negative images recalled increased with age. In another study examining the

positivity effect with healthcare information, the ratio of positive to negative healthcare messages remembered increased with age (Shamaskin, Mikels, & Reed, 2010). Within the literature on aging and affect, a general finding is that there are decreases in negative affect with age. One noteworthy study using a longitudinal design with a large sample (n = 2, 804) found that negative affect decreased with increasing age across four generations of families (Charles, Reynolds, & Gatz, 2001). Age differences in positive affect, on the other hand, are less conclusive (Charles et al. 2001).

Considering these findings from developmental psychology in the context of the present study, one could reasonably expect that heart transplant and the years that follow would require a great deal of emotion regulation and adjustment. In this long-term adjustment process, the older patients may have been more likely than the younger patients to avoid negative interactions and negative affect, which would therefore improve the ratio of positive to negative experiences. While the underlying motivation for this effortful avoidance of negative experiences is to construct a social environment that enhances well-being (Carstensen et al., 2003), these factors likely also explain why the older patients in the present study reported less depression and negative affect than the younger patients. It may also be the case that the older patients demonstrated less depression in conjunction with lowered levels of heart transplant-related stress and more satisfaction with their social support. While the present study is cross-sectional and no causational conclusions can be drawn, it is probable that several of the main outcome variables influenced each other since many of them are correlated with each other (Table 1).

It is important to note that not only did older patients have lower average levels of depression than the younger patients, but there were also significantly more younger patients

that reported clinical levels of depression than the older patients. This finding is in contrast with some previous literature examining increasing age and risk for depression. A general finding in the literature is that older adults with poorer health have relatively high levels of depression (Hybels & Blazer, 2003) while healthy, normally functioning older adults are not at any greater risk for depression than younger adults (Jorm, 2000; Roberts, Kaplan, Shema, & Strawbridge, 1997). The present findings, on the other hand, demonstrate that more than 5 years after heart transplant, the older patient population had significantly lower levels of depression than the younger patients, despite both age groups representing the same medical population. Another study of heart failure patients found similar results, in which younger patients had a higher incidence of depression than older patients (Gottlieb et al., 2004). These researchers suggested the finding was due to the younger patients' disparity between their functional status and expectation for functioning. In the present study, it is not clear the impact of negative affect on depression prevalence, except that the variables were highly correlated with each other. A future longitudinal study could explore this relationship further to determine how more short-term mood states, as assessed by the *Positive and Negative Affect Schedule* measure in the present study, might contribute to the long-term development of depression.

Composite variable. According to DeVellis (2003), one purpose of a factor analysis is to provide a means of explaining variation among many variables using relatively few newly created variables, or factors. In the present study, the composite variable was calculated after conducting a factor analysis of the main outcome variables to determine if certain variables varied in a similar manner to each other and reflected an unobserved latent variable. The factor analysis revealed a one-factor solution that included six variables: depression, post-transplant symptom distress, satisfaction with quality of life, stress related to the heart transplant, overall

functioning, and negative affect. DeVellis (2003) explains that one can examine which items best exemplify the factor, or have the largest loadings on a particular factor, and this may clarify the nature of the factor in question.

In the present study, mood, quality of life, and general emotional experience seem to be conceptually linked and loaded heavily on the same factor, which likely reflect an underlying factor such as adjustment. In addition to the individual variables differences found between the older and younger groups, the older patients again scored better on the composite variable compared to the younger patients. This finding is particularly interesting since two variables, post-transplant symptom distress and overall functioning, loaded highly on the latent variable in the factor analysis, but there were no significant age differences found when these variables were analyzed individually. Additionally, several variables (difficulty with adherence, actual adherence, and satisfaction with social support) did demonstrate significant age differences when analyzed individually, however they did not load highly onto the latent variable in the factor analysis. One possible explanation for this finding is that the latent variable may reflect more of the personal emotional adjustment aspect of the post-transplant period, while adherence and satisfaction with social support are further removed from the within-person, individual adjustment process.

Nonsignificant Age Differences

There were no differences between the older and younger patients in regards to overall functioning, post-transplant symptom distress, or use of positive coping strategies. While these differences neared significance values and trended in the hypothesized direction, they did not reach the adequate level of significance after adjusting with the Bonferroni correction. Regarding overall functioning, it may be the case that the overall score of the *Sickness Impact*

77

Profile did not capture age differences that might exist. For example, some previous studies have found that older patients have better mental health outcomes compared to younger patients, while younger patients report better physical health outcomes (Littlefield et al., 1996; Martinelli et al., 2007). In the present study, this same pattern may have existed, but significant differences could have been masked since the *Sickness Impact Profile* assesses overall health functioning, including both physical and mental components of health.

A similar explanation might account for the nonsignificant differences in post-transplant symptom distress. One might expect that the older patients would be better equipped to be less bothered by the symptom due to the previously mentioned age-related changes in emotion regulation and experiences of stress. However, since the *Heart Transplant Symptom Checklist* assesses physical symptoms, and research has shown that physical health tends to be worse in older patients (Littlefield et al., 1996; Martinelli et al., 2007), it is difficult to determine if any genuine age differences in symptom distress were mitigated due to the measure's emphasis on the presence of physical symptoms.

Lastly, the nonsignificant age differences in regards to use of positive coping strategies may be due to known differences in coping strategies among older and younger adults. Some researchers have concluded based on studies of coping strategy use and effectiveness that older adults may be more effective copers by proactively avoiding stressful situations in which coping would be necessary (Aldwin et al., 1996). Other researchers within the coping literature field make the distinction between *automatic* and *intentional* coping, in which unintentional and habitual coping behaviors may be adaptive but without conscious awareness or control (Cramer, 1998). In this regard, perhaps the older patients in the present study utilized coping strategies in

78

an unintentional or automatic manner, and thus would not endorse using explicit or intentional positive coping strategies.

Age Differences Across Three Groups

The purpose of examining age differences through the "older group" compared to "younger group" dichotomy was to maintain consistency with previous literature and reflect the current practice in transplant recommendations with a degree of external validity. There are some limitations with comparing two age groups and drawing conclusions based on group means. First, the two age groups were not equal in terms of sample size or variance, however these differences were addressed statistically. Given the large sample size for the patient population in the entire study, there was an adequate number of participants in the older adult group to be able to conduct the necessary statistical analyses. Additionally, when the homogeneity of variance assumption was violated, an alternative statistical test, such as the Brown-Forsythe F-ratio, was used since it is known as robust when this assumption is broken (Field, 2009).

Another potential limitation of comparing patients divided into two age groups is that this simplifies the patient population, particularly in the younger age group. The age range of participants varied quite a bit between the younger and older groups (younger group range: 21-59 years old; older group range: 60-75 years old). It is possible that the youngest patients in the younger age group (< 45 years old at time of transplant) may have had a different adjustment process that was unique compared to the older patients in the younger age group (45-59 years old at time of transplant). This was an important consideration to explore, since the youngest patients' scores on the various measures may have been lowering the average score of the younger group as a whole, potentially amplifying the significant age differences results.

79

This alternative explanation for the main findings, however, was not supported. After dividing the patient population into the previously explained younger (<45 years old), middle-aged (45-59 years old), and older (>60 years old) groups, the older group continued to show better adjustment to the outcome measures of interest. For the variables quality of life, difficulty with adherence, actual adherence, satisfaction with social support, stress related to the heart transplant, depression, and negative affect, the older patient group scored significantly better than the younger and middle-aged groups. Additionally, the middle-aged group tended to score similarly to the younger patient group across these variables, with the exception of negative affect in which the youngest group showed the highest levels of negative affect, followed by the middle-aged group and then the older group in a linear fashion. In regards to overall health functioning, as measured by the *Sickness Impact Profile,* the middle-aged group scored significantly poorer than both the younger and older patient groups. Perhaps the older patients' scores were relatively better than the middle-aged group due to enhanced emotional adjustment, while the youngest patients' scores were better due to presumably better physical functioning that occurs with youth. Lastly, there were no significant differences among the three age groups in regards to post-transplant symptom distress, which could be expected given that there were no age differences in the two-group comparison.

Exploring the primary findings further through the three-group analysis helps elucidate the main age differences seen across many of the outcome variables. It is clear that there is not a younger subset of patients (<45 years old) in the younger group that is functioning differently from the middle-aged patients also included in the younger patient group. In fact, it appears that the middle-aged patients scored very similarly to the younger patients and differently from the older patients. From this finding, one can conclude more confidently that the scores of the

80

younger group in the main two-group analyses are accurate reflections of all patients included in the group. The older patient sample does seem distinct from both the middle-aged the younger group, which further supports the various theoretical explanations for older adults maintaining unique coping and adjustment abilities in the face of a major health stressor.

Clinical Impact

In the present study each age groups' calculated mean scale scores were converted back into the raw scores in order to interpret how the two age groups actually differed in their reporting on the scales. On the majority of the scales, the response options were limited in range; many scales had a 4-point scale, while some scales had up to a 7-point scale. The older and younger patients differed in raw scale scores by often less than one point on the original scales. On the *Sickness Impact Profile*, however, there is a larger range of possible scores and the difference in scores between the older and younger patients becomes more evident. Normative data studies for the *Sickness Impact Profile* demonstrate that general adult population has a score of 5 (Lipsett et al., 2000), while patients with rheumatoid arthritis scored a 15.9 (Deyo, Inui, Leininger, & Overman, 1982) and patients with chronic lower back pain scored a 23.8 (Follick, Smith, & Ahern, 1984). The older patients in the present study scored a 7.7 and the younger patients scored a 9.9, which was not significantly different after the conservative Bonferroni correction, but there may be some clinical meaning that can be drawn from this finding. All patients in the study were functioning more poorly than the general population normative sample, but the older patient sample scored 54% higher than the general population while the younger patient sample scored 98% higher. There is also evidence on the *Cardiac Depression Scale* of a clinically meaningful difference between the older and younger patients' scores. Based on the chi-square analysis, the odds of a patient scoring in the clinical range on the

Cardiac Depression Scale was 2.03 times higher if the patient was a younger adult than if he or she was an older adult.

While the main findings from the present study demonstrate that the two age groups are significantly different from each other across outcomes, statisticians and research methodologists often recommend supplementing statistical significance testing in some manner (Kazdin, 2010). One of the major concerns or limitations with relying solely on null hypothesis and statistical significance testing is that large sample sizes will often result in statistically significant differences, regardless of whether they truly exist or not. Kazdin (2010) suggests that it is best practice to estimate the strength of an effect, in addition to statistical significance testing in order to determine the magnitude of differences between groups. To determine the magnitude of an effect, effect size is often calculated. Effect size is a useful statistic since it can be interpreted in standard deviation units and thus compared across different outcome measures.

As a supplement to the main findings of statistically significant differences between the older and younger patients, effect size was also calculated for each comparison. For the variables in which there was a statistically significant difference, effect sizes ranged from .25 to .47, which represent small to approximately medium effects (Cohen, 1988). These differences can be clinically meaningful, however, when considering the context of the dependent and independent variables in the analyses. Prentice and Miller (1992) argue that a large effect size is not necessarily the only way to show an important effect. They make the case that a small effect can be noteworthy if it was created through relatively minimal changes in the independent variable. In the present study, the continuous age variable was altered by dividing patients into two groups based on a seemingly arbitrary distinction between older and younger patients, based on previous literature and current transplant practices. Larson, Hoyt, and McCullough (2001)

emphasize that one must assess the importance of the outcome in conjunction with how supposedly minor the independent variable's influence on the outcome. Since quality of life and other facets of adjustment are presumably multi-determined and influenced by a variety of factors, it is a noteworthy finding that the relatively arbitrary distinction of age group produces a small to medium effect on substantial post-transplant outcomes.

Limitations and Future Directions

There are a number of limitations in the present study that should be noted in the interpretation of the findings. First, the patients included in the study were only those patients who agreed to participate. This self-selected group of patients may have agreed to participate if they felt well enough to participate, which could have overestimated the quality of life measure and underestimated the mood and heart transplant symptom and stress measures. On the other hand, patients who were functioning particularly well may have returned to work or have been too busy to wish to participate in the study. Either of these possibilities may have inflated or deflated overall mean scores. For instance, younger heart transplant patients that had good psychosocial functioning may have not participated in the study if they had returned to work, or alternatively, older patients who had very poor functioning after the transplant may have been too ill and chosen not to participate.

Similarly to the self-selected limitation previously mentioned, another major limitation of this study is that the patient sample consisted only of patients who survived at least 5 years post-transplant and were eligible to be recruited for the study. While the present study suggests that across a variety of psychosocial outcomes, older patients demonstrate better adjustment after a heart transplant than younger patients, these findings are based on a sample of patients who survived at least 5 years after the surgery. The patients who did not survive at least 5 years

83

presumably had poorer health functioning and may have also had poorer psychological functioning. Of the original 1,437 patients transplanted at the four medical centers, 884 patients between 5 and 10 years post-heart transplantation were eventually eligible for potential recruitment. 553 patients were ineligible for recruitment, including 386 patients who died prior to consent and obviously could not be recruited for the study. Unfortunately, data are not available regarding these patients that died prior to consent. If the data were available, it would be important to explore these patient characteristics, particularly the portion of patients who would qualify as older or younger patients. Given the mixed findings in the literature regarding age differences in mortality outcomes for heart transplant patients, knowing how many older and younger patients died prior to consenting to be in the present study would be beneficial for interpreting the main findings. Future research using long-term follow-up designs should strive to collect additional data on patients who did not enroll in the study. If there are age differences in the make up of the groups of patients who enrolled and did not enroll, it would be useful to know whether patients did not enroll due to poor functioning, exceptionally good functioning, or death prior to the enrollment period.

Another limitation of the study is that patients were drawn from four different transplant centers, each of which has its own transplant criteria and patient selection process. It may be the case that at one of these transplant centers, the transplant team maintains stricter guidelines or has a more rigorous pre-transplant evaluation process than other transplant centers. Some research has demonstrated that there can be large discrepancies in the criteria used and rates of refusal for transplant based on psychological reasons (Levenson & Olbrisch, 1993). These researchers found that cardiac transplant programs are the most stringent in terms of rates of refusal to transplant and in criteria, however they concluded that a better consensus is needed in

84

regards to criteria for transplant, since even seemingly straightforward variables such as age can have unfair or unclear effects on transplantation access. The sample in the present study included, and was thus restricted to, only patients who were deemed eligible for transplant at each particular transplant center. Each transplant center likely had different criteria and standards that presumably impacted the characteristics of the patients who received heart transplants at that center.

This limitation was partially addressed by including the transplant center as a covariate in the independent samples t-tests. There was an effect of transplant center in regards to adherence; at two of the transplant centers, the older patients reported better adherence than the younger patients, while at the other two centers there were no significant age differences in adherence. At the two centers where there were no evident age differences, the transplant teams may have carefully evaluated potential adherence issues in their pre-transplant evaluation for all patients or emphasized its importance in the post-operative recovery period. For all other outcomes, however, transplant center was not a significant covariate, and one can assume that the variance in the outcome variables of interest was not due to variations in the transplant centers. Future research could benefit by conducting a more formal evaluation of each transplant center's screening and pre-transplant evaluation process. Previous studies have used a survey methodology for assessing process, criteria, and outcomes of psychosocial evaluation of transplant candidates (Levenson & Olbrisch, 1993; Olbrisch & Levenson, 1991). A future study using a multi-site design could use this survey or a similar survey to evaluate more generally how transplant centers differ in their selection process for transplant candidates. This information would allow researchers to make comparisons across sites, hypothesize about the

85

impact of the criteria on which patients are more likely to receive a transplant at each site, and then consider how this might effect the outcome variable of interest.

Summary of Contributions

The current study sought to compare older and younger patients in regards to psychosocial functioning and adjustment, since studies in heart transplant literature often compare these patient groups in mortality and morbidity outcomes. Overall, the findings suggest that older patients appear to report better psychosocial functioning after heart transplant than younger patients. These age differences in functioning are seen across a range of outcome measures, capturing significant variation in emotional experience, social support functionality, important health behaviors such as adherence, and overall quality of life. Additionally, further group analyses clarified that the older patients actually do represent a distinct group that functions differently from the middle-aged and youngest patients.

A strength to the present study is that the data set has unique characteristics not often seen in other heart transplant research studies. This study has a relatively large sample compared to many other heart transplant studies, and the sample included a large enough age distribution to be able to divide the participants into dichotomous groups and conduct analyses to depict meaningful group comparisons. Additionally, the sample included patients from multiple transplant centers, whereas many previous studies of heart transplant patients were conducted at single institutions. Patients were assessed from geographically diverse areas, which increased the representativeness of the sample. Therefore, the results can be more confidently generalized to the larger population of heart transplant recipients, particularly since transplant center was not a significant covariate for most of the outcomes. This study also examined patients who were at least 5 years post-transplant, and thus the results represent an assessment of

86

functioning after a long-term follow-up period. The long-term follow-up is an important strength to the study, since certain psychologically-influenced elements of the recovery period worsen over time, such as adherence rates (Dew et al., 1996).

Lastly, the present study is the only study to the author's knowledge that has an a priori exploration of age differences, focusing specifically on comparing age groups of patients and exploring a variety of outcomes. Previous studies have either found age differences in psychological outcomes as a secondary finding (Bennett et al., 2001; Evangelista et al., 2001; Koivula et al., 2009), or they focused primarily on age differences but only in the context of a few psychological domains (Coffman et al., 1997; Martinelli et al., 2007). Additionally, there are numerous studies that focus on patient age and medical outcomes, including survival rates (Blanche et al., 1996; Borkon et al., 1999; Demers et al., 2003; Marelli et al., 2008), rejection rates (Bradley, 2002), infection and malignancy rates (Tjang et al., 2008), and post-operative hospital stay length (Blanche et al., 1996; Morgan et al., 2003). While it is critical to assess which patients are most likely to have a medically successful transplant, the findings from these medical outcomes studies remain mixed in regards to age. It is at least equally important to evaluate psychological outcomes and how the surviving patients are functioning and adjusting to their transplant. Both quality and quantity of life benefits are typically considered simultaneously when medical professionals and the public are asked how to prioritize individuals for organ allocation (Tong et al., 2010). The present study offers a unique contribution to the literature in terms of the emphasis on age differences, and it adds to the smaller body of research that examines quality of life in transplant patients. There is continued debate regarding the role of age in transplant decision-making (Bramstedt, 2001; Cairney, 2000; Kerstein & Bognar, 2010), even recently with former Vice President Dick Cheney's

consideration of a heart transplant (Cappon, 2011). This study hopes to serve as an important contribution in balancing the heart transplant literature, as well as highlighting the need for continued reevaluation of changing patient demographics and how this translates to potentially necessary changes in policy and practice.

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List of References

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91

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Appendix

HEART TRANSPLANT SYMPTOM CHECKLIST

Listed below are many symptoms or problems that a person might have after a heart transplant. PLEASE CHECK (YES OR NO) IF YOU HAVE HAD THIS SYMPTOM <u>DURING THE LAST 6 MONTHS</u>. IF YOU SAID "YES"; PLEASE RATE HOW MUCH YOU WERE BOTHERED BY EACH SYMPTOM, BY CIRCLING A NUMBER FROM 0-3. The rating scale for the numbers is as follows:

0	=	not bothered at all
1	=	slightly bothered
2	=	moderately bothered
3	=	very bothered

IF YOU SAID "NO", PLEASE GO ON TO THE NEXT QUESTION.

		Did you have this symptom in the last 6 months?		If you have had this symptom, how much were you bothered by it?			
		Yes	No				
1.	chest pain (angina)	____	____	0	1	2	3
2.	chest tightness	____	____	0	1	2	3
3.	wheezing	____	____	0	1	2	3
4.	coughing	____	____	0	1	2	3
5.	difficulty breathing when sitting	____	____	0	1	2	3
6.	difficulty breathing when lying down	____	____	0	1	2	3
7.	difficulty breathing when walking or doing something	____	____	0	1	2	3
8.	fast heart rate	____	____	0	1	2	3
9.	slow heart rate	____	____	0	1	2	3
10.	pounding heart	____	____	0	1	2	3
11.	heart skipping a beat or jumping	____	____	0	1	2	3
12.	swelling in abdomen	____	____	0	1	2	3
13.	swelling in legs or feet	____	____	0	1	2	3
14.	difficulty sleeping	____	____	0	1	2	3
15.	frequent nightmares	____	____	0	1	2	3
16.	poor appetite	____	____	0	1	2	3

1

PLEASE CHECK (YES OR NO) IF YOU HAVE HAD THIS SYMPTOM <u>DURING THE LAST 6 MONTHS</u>. IF YOU SAID "YES"; PLEASE RATE HOW MUCH YOU WERE BOTHERED BY EACH SYMPTOM, BY CIRCLING A NUMBER FROM 0-3. The rating scale for the numbers is as follows:

0	=	not bothered at all
1	=	slightly bothered
2	=	moderately bothered
3	=	very bothered

IF YOU SAID "NO", PLEASE GO ON TO THE NEXT QUESTION.

		Did you have this symptom in the last 6 months?		If you have had this symptom, how much were you bothered by it?			
		Yes	No				
17.	problems with taste	____	____	0	1	2	3
18.	nausea	____	____	0	1	2	3
19.	vomiting	____	____	0	1	2	3
20.	feeling hungry all the time	____	____	0	1	2	3
21.	overeating	____	____	0	1	2	3
22.	strong craving for certain foods	____	____	0	1	2	3
23.	stomach pain	____	____	0	1	2	3
24.	upset stomach	____	____	0	1	2	3
25.	bloated feeling in stomach	____	____	0	1	2	3
26.	diarrhea or loose bowel movements	____	____	0	1	2	3
27.	constipation	____	____	0	1	2	3
28.	weight loss	____	____	0	1	2	3
29.	weight gain	____	____	0	1	2	3
30.	weakness in whole body	____	____	0	1	2	3
31.	weakness on one side of body	____	____	0	1	2	3
32.	weakness in arms	____	____	0	1	2	3
33.	weakness in legs	____	____	0	1	2	3

2

PLEASE CHECK (YES OR NO) IF YOU HAVE HAD THIS SYMPTOM <u>DURING THE LAST 6 MONTHS</u>. IF YOU SAID "YES"; PLEASE RATE HOW MUCH YOU WERE BOTHERED BY EACH SYMPTOM, BY CIRCLING A NUMBER FROM 0-3. The rating scale for the numbers is as follows:

0	=	not bothered at all
1	=	slightly bothered
2	=	moderately bothered
3	=	very bothered

IF YOU SAID "NO", PLEASE GO ON TO THE NEXT QUESTION.

		Did you have this symptom in the last 6 months?		If you have had this symptom, how much were you bothered by it?			
		Yes	No				
34.	tiredness	___	___	0	1	2	3
35.	sleepiness	___	___	0	1	2	3
36.	dizziness	___	___	0	1	2	3
37.	fainting or passing out	___	___	0	1	2	3
38.	feeling restless	___	___	0	1	2	3
39.	feeling anxious or apprehensive	___	___	0	1	2	3
40.	tremors or shaking of hands or body	___	___	0	1	2	3
41.	cold feeling in hands or feet	___	___	0	1	2	3
42.	cramps in hands or feet or legs	___	___	0	1	2	3
43.	burning, throbbing, or numbness in hands or feet	___	___	0	1	2	3
44.	urinating less than usual	___	___	0	1	2	3
45.	urinating more than usual	___	___	0	1	2	3
46.	blurred or unclear eyesight (even with glasses on)	___	___	0	1	2	3
47.	puffy eyes or face	___	___	0	1	2	3
48.	headaches	___	___	0	1	2	3
49.	seizures (convulsions)	___	___	0	1	2	3

3

PLEASE CHECK (YES OR NO) IF YOU HAVE HAD THIS SYMPTOM <u>DURING THE LAST 6 MONTHS</u>. IF YOU SAID "YES"; PLEASE RATE HOW MUCH YOU WERE BOTHERED BY EACH SYMPTOM, BY CIRCLING A NUMBER FROM 0-3. The rating scale for the numbers is as follows:

	0	=	not bothered at all
	1	=	slightly bothered
	2	=	moderately bothered
	3	=	very bothered

IF YOU SAID "NO", PLEASE GO ON TO THE NEXT QUESTION.

		Did you have this symptom in the last 6 months?		If you have had this symptom, how much were you bothered by it?			
		Yes	No				
50.	mouth sores	____	____	0	1	2	3
51.	overgrowth of gums	____	____	0	1	2	3
52.	easy bruising	____	____	0	1	2	3
53.	sensitive or fragile skin	____	____	0	1	2	3
54.	infection of fingernails or toenails	____	____	0	1	2	3
55.	yellow skin or eyes	____	____	0	1	2	3
56.	excessive hairiness	____	____	0	1	2	3
57.	excessive sweating	____	____	0	1	2	3
58.	acne (skin breaking out)	____	____	0	1	2	3
59.	change in menstrual periods	____	____	0	1	2	3
60.	change in amount of menstrual bleeding	____	____	0	1	2	3
61.	decrease in sexual desire	____	____	0	1	2	3
62.	increase in sexual desire	____	____	0	1	2	3
63.	difficulty in sexual performance	____	____	0	1	2	3
64.	feeling less masculine or less feminine	____	____	0	1	2	3

4

106

PLEASE CHECK (YES OR NO) IF YOU HAVE HAD THIS SYMPTOM <u>DURING THE LAST 6 MONTHS</u>. IF YOU SAID "YES"; PLEASE RATE HOW MUCH YOU WERE BOTHERED BY EACH SYMPTOM, BY CIRCLING A NUMBER FROM 0-3. The rating scale for the numbers is as follows:

0	=	not bothered at all
1	=	slightly bothered
2	=	moderately bothered
3	=	very bothered

IF YOU SAID "NO", PLEASE GO ON TO THE NEXT QUESTION.

		Did you have this symptom in the last 6 months?		If you have had this symptom, how much were you bothered by it?			
		Yes	No				
65.	nervousness	____	____	0	1	2	3
66.	irritability	____	____	0	1	2	3
67.	mood swings	____	____	0	1	2	3
68.	feeling afraid	____	____	0	1	2	3
69.	difficulty keeping temper under control	____	____	0	1	2	3
70.	feeling sad	____	____	0	1	2	3
71.	feeling depressed	____	____	0	1	2	3
72.	feeling hopeless	____	____	0	1	2	3
73.	feeling helpless	____	____	0	1	2	3
74.	feeling of lack of control over your life	____	____	0	1	2	3
75.	feeling unusually energetic	____	____	0	1	2	3
76.	trouble concentrating	____	____	0	1	2	3
77.	trouble remembering things	____	____	0	1	2	3
78.	trouble speaking	____	____	0	1	2	3
79.	feeling confused or disoriented	____	____	0	1	2	3
80.	hallucinations (hearing or seeing imaginary things)	____	____	0	1	2	3
81.	feeling persecuted or that everyone is out to get you	____	____	0	1	2	3

5

PLEASE CHECK (YES OR NO) IF YOU HAVE HAD THIS SYMPTOM <u>DURING THE LAST 6 MONTHS</u>. IF YOU SAID "YES"; PLEASE RATE HOW MUCH YOU WERE BOTHERED BY EACH SYMPTOM, BY CIRCLING A NUMBER FROM 0-3. The rating scale for the numbers is as follows:

0	=	not bothered at all
1	=	slightly bothered
2	=	moderately bothered
3	=	very bothered

IF YOU SAID "NO", PLEASE GO ON TO THE NEXT QUESTION.

		Did you have this symptom in the last 6 months?		If you have had this symptom, how much were you bothered by it?			
		Yes	No				
82.	losing interest in life	____	____	0	1	2	3
83.	change in facial features	____	____	0	1	2	3
84.	change in body features	____	____	0	1	2	3
85.	fever or chills	____	____	0	1	2	3
86.	sores on body: where? _____	____	____	0	1	2	3
87.	unexplained bumps or lumps on body: where? _____	____	____	0	1	2	3
88.	bleeding: where? _____	____	____	0	1	2	3
89.	pain: where? _____	____	____	0	1	2	3
	where? _____			0	1	2	3
	where? _____			0	1	2	3
90.	any other symptoms not listed above?			0	1	2	3
	please describe _____			0	1	2	3
	please describe _____			0	1	2	3
	please describe _____			0	1	2	3

6

HEART TRANSPLANT STRESSOR SCALE

Listed below are many things that might cause stress for a person who has had a heart transplant. PLEASE CHECK (YES OR NO) IF YOU HAVE HAD THIS STRESS <u>DURING THE LAST 6 MONTHS</u>. IF YOU SAID "YES", PLEASE RATE HOW STRESSFUL EACH OF THESE THINGS HAS BEEN FOR YOU BY CIRCLING A NUMBER FROM 0-3. The rating scale for the numbers is as follows:

0	=	not stressful at all
1	=	slightly stressful
2	=	fairly stressful
3	=	very stressful

IF YOU SAID "NO", PLEASE GO ON TO THE NEXT QUESTION.

		Did you have this stressor in the last 6 months?		If you have had this stressor, how stressful has it been for you?			
		Yes	No				
1.	Getting your life back to normal	____	____	0	1	2	3
2.	Worrying that the new heart might not work	____	____	0	1	2	3
3.	Being afraid that your heart will stop beating	____	____	0	1	2	3
4.	Worrying about being alone if something happens to your heart	____	____	0	1	2	3
5.	Worrying that the doctors won't be able to help you if something happens to your heart	____	____	0	1	2	3
6.	Worrying about dying	____	____	0	1	2	3
7.	Not having someone close-by in case you have problems or questions	____	____	0	1	2	3
8.	Having to take a lot of medications	____	____	0	1	2	3
9.	Trying to remember to take all your medications	____	____	0	1	2	3
10.	Having side effects from your medications	____	____	0	1	2	3
11.	Physical changes caused by steroids	____	____	0	1	2	3
12.	Mental and emotional changes caused by steroids	____	____	0	1	2	3
13.	Feeling guilty about not being able to control your emotions	____	____	0	1	2	3

1

PLEASE CHECK (YES OR NO) IF YOU HAVE HAD THIS STRESS <u>DURING THE LAST 6 MONTHS</u>. IF YOU SAID "YES", PLEASE RATE HOW STRESSFUL EACH OF THESE THINGS HAS BEEN FOR YOU BY CIRCLING A NUMBER FROM 0-3. The rating scale for the numbers is as follows:

0	=	not stressful at all
1	=	slightly stressful
2	=	fairly stressful
3	=	very stressful

IF YOU SAID "NO", PLEASE GO ON TO THE NEXT QUESTION.

		Did you have this stressor in the last 6 months?		If you have had this stressor, how stressful has it been for you?			
		Yes	No				
14.	Having to make frequent changes in your medications	____	____	0	1	2	3
15.	Knowing you have to take medications for the rest of your life	____	____	0	1	2	3
16.	Having heart biopsies	____	____	0	1	2	3
17.	Waiting for the biopsy results	____	____	0	1	2	3
18.	Worrying about having acute rejection	____	____	0	1	2	3
19.	Having an episode of acute rejection	____	____	0	1	2	3
20.	Worrying about having chronic rejection	____	____	0	1	2	3
21.	Developing chronic rejection	____	____	0	1	2	3
22.	Worrying about getting an infection	____	____	0	1	2	3
23.	Taking precautions to avoid infection	____	____	0	1	2	3
24.	Having an infection	____	____	0	1	2	3
25.	Worrying about getting high blood pressure	____	____	0	1	2	3
26.	Having your blood pressure go up too high	____	____	0	1	2	3
27.	Worrying about getting diabetes	____	____	0	1	2	3
28.	Having diabetes	____	____	0	1	2	3
29.	Worrying about getting cancer	____	____	0	1	2	3

2

PLEASE CHECK (YES OR NO) IF YOU HAVE HAD THIS STRESS <u>DURING THE LAST 6 MONTHS</u>. IF YOU SAID "YES", PLEASE RATE HOW STRESSFUL EACH OF THESE THINGS HAS BEEN FOR YOU BY CIRCLING A NUMBER FROM 0-3. The rating scale for the numbers is as follows:

0	=	not stressful at all
1	=	slightly stressful
2	=	fairly stressful
3	=	very stressful

IF YOU SAID "NO", PLEASE GO ON TO THE NEXT QUESTION.

		Did you have this stressor in the last 6 months?		If you have had this stressor, how stressful has it been for you?			
		Yes	No				
30.	Having cancer	____	____	0	1	2	3
31.	Worrying about getting back or spine problems	____	____	0	1	2	3
32.	Having back or spine problems	____	____	0	1	2	3
33.	Understanding what the doctors and nurses tell you about your illness and tests	____	____	0	1	2	3
34.	Having your questions answered by staff	____	____	0	1	2	3
35.	Needing help with taking care of yourself at home	____	____	0	1	2	3
36.	Needing help with chores around the house and yard	____	____	0	1	2	3
37.	Needing help with taking care of the children (or elderly parents)	____	____	0	1	2	3
38.	Having your spouse and/or children take over some of your responsibilities	____	____	0	1	2	3
39.	Having to depend on others a lot	____	____	0	1	2	3
40.	Trying to take a more active role in running the household	____	____	0	1	2	3
41.	Trying to participate in more social activities	____	____	0	1	2	3
42.	Trying to find the energy for hobbies or leisure activities	____	____	0	1	2	3

3

PLEASE CHECK (YES OR NO) IF YOU HAVE HAD THIS STRESS <u>DURING THE LAST 6 MONTHS</u>. IF YOU SAID "YES", PLEASE RATE HOW STRESSFUL EACH OF THESE THINGS HAS BEEN FOR YOU BY CIRCLING A NUMBER FROM 0-3. The rating scale for the numbers is as follows:

0	=	not stressful at all
1	=	slightly stressful
2	=	fairly stressful
3	=	very stressful

IF YOU SAID "NO", PLEASE GO ON TO THE NEXT QUESTION.

		Did you have this stressor in the last 6 months?		If you have had this stressor, how stressful has it been for you?			
		Yes	No				
43.	Feeling worn out	_____	_____	0	1	2	3
44.	Making changes in your lifestyle	_____	_____	0	1	2	3
45.	Having to follow a specific health schedule	_____	_____	0	1	2	3
46.	Increasing your physical activity	_____	_____	0	1	2	3
47.	Keeping up an exercise program	_____	_____	0	1	2	3
48.	Trying to keep on a special diet	_____	_____	0	1	2	3
49.	Having to watch your fluid intake	_____	_____	0	1	2	3
50.	Trying to keep your weight under control	_____	_____	0	1	2	3
51.	Staying away from smoking	_____	_____	0	1	2	3
52.	Being away from your job (or school)	_____	_____	0	1	2	3
53.	Worrying about going back to work (or school)	_____	_____	0	1	2	3
54.	Starting back to work (or school)	_____	_____	0	1	2	3
55.	Worrying about how well you're doing on your job (or at school)	_____	_____	0	1	2	3
56.	Having to take time off from work (or school) for your check-ups	_____	_____	0	1	2	3
57.	Worrying about losing your job	_____	_____	0	1	2	3
58.	Being unemployed because of your illness	_____	_____	0	1	2	3

4

PLEASE CHECK (YES OR NO) IF YOU HAVE HAD THIS STRESS <u>DURING THE LAST 6 MONTHS</u>. IF YOU SAID "YES", PLEASE RATE HOW STRESSFUL EACH OF THESE THINGS HAS BEEN FOR YOU BY CIRCLING A NUMBER FROM 0-3. The rating scale for the numbers is as follows:

0	=	not stressful at all
1	=	slightly stressful
2	=	fairly stressful
3	=	very stressful

IF YOU SAID "NO", PLEASE GO ON TO THE NEXT QUESTION.

		Did you have this stressor in the last 6 months?		If you have had this stressor, how stressful has it been for you?			
		Yes	No				
59.	Trying to find a new job if you don't have one	____	____	0	1	2	3
60.	Decreased income because of your illness	____	____	0	1	2	3
61.	Paying for your medications	____	____	0	1	2	3
62.	Paying your hospital and doctor bills	____	____	0	1	2	3
63.	Having your family worry about you	____	____	0	1	2	3
64.	Seeing your family be over-protective of you	____	____	0	1	2	3
65.	The effect of your illness on relationships with your spouse and family	____	____	0	1	2	3
66.	Participating in sexual activity	____	____	0	1	2	3
67.	Worrying about the progress you're making	____	____	0	1	2	3
68.	Comparing yourself to other transplant patients	____	____	0	1	2	3
69.	Hearing that a transplant patient has died or isn't doing well	____	____	0	1	2	3
70.	Taking your vital signs	____	____	0	1	2	3
71.	Taking care of yourself at home	____	____	0	1	2	3
72.	Worrying that your family won't know what to do if you get sick	____	____	0	1	2	3
73.	Worrying about how to get medical care if you get sick while you're on vacation or away from home	____	____	0	1	2	3

5

113

PLEASE CHECK (YES OR NO) IF YOU HAVE HAD THIS STRESS <u>DURING THE LAST 6 MONTHS</u>. IF YOU SAID "YES", PLEASE RATE HOW STRESSFUL EACH OF THESE THINGS HAS BEEN FOR YOU BY CIRCLING A NUMBER FROM 0-3. The rating scale for the numbers is as follows:

0	=	not stressful at all
1	=	slightly stressful
2	=	fairly stressful
3	=	very stressful

IF YOU SAID "NO", PLEASE GO ON TO THE NEXT QUESTION.

		Did you have this stressor in the last 6 months?		If you have had this stressor, how stressful has it been for you?			
		Yes	No				
74.	Watching for problems that need follow-up	_____	_____	0	1	2	3
75.	Having to go in for frequent check-ups and tests	_____	_____	0	1	2	3
76.	Being cared for by many different doctors and nurses when you go for check-ups	_____	_____	0	1	2	3
77.	Worrying that you might have to go back into the hospital	_____	_____	0	1	2	3
78.	Worrying about losing your insurance	_____	_____	0	1	2	3
79.	Knowing you shouldn't get pregnant because of your heart transplant	_____	_____	0	1	2	3
80.	The amount of control you have over your life	_____	_____	0	1	2	3
81.	Not knowing what will happen in the future because of your illness	_____	_____	0	1	2	3

ARE THERE ANY OTHER THINGS THAT ARE <u>NOT</u> LISTED ABOVE THAT HAVE CAUSED YOU STRESS DURING THE LAST SIX MONTHS EVEN IF THEY HAVE NOTHING TO DO WITH YOUR HEART TRANSPLANT (SUCH AS FAMILY CONFLICT, MOVING, DEATH OF A LOVED ONE OR ANYTHING ELSE)? WOULD YOU PLEASE LIST THESE THINGS BELOW AND THEN RATE HOW STRESSFUL EACH OF THEM HAS BEEN FOR YOU.

82.	_____	1	2	3
83.	_____	1	2	3
84.	_____	1	2	3

6

ASSESSMENT OF PROBLEMS WITH THE HEART TRANSPLANT REGIMEN

PART A

PLEASE PLACE A "CHECKMARK" NEXT TO THE RESPONSE THAT BEST DESCRIBES HOW MUCH DIFFICULTY YOU HAD FOLLOWING YOUR HEART TRANSPLANT REGIMEN IN THE LAST 6 MONTHS.

1. How much difficulty did you have in the last 6 months taking all your anti-rejection medications in general?

   _____ no difficulty
   _____ a little difficulty
   _____ moderate difficulty
   _____ a lot of difficulty

   If you did have difficulty, please state why:

   _____

2. How much difficulty did you have in the last 6 months taking your cyclosporine (Sandimmune or Neoral or SangCya) as prescribed?

   _____ I am not on cyclosporine
   _____ no difficulty
   _____ a little difficulty
   _____ moderate difficulty
   _____ a lot of difficulty

   If you did have difficulty, please state why:

   _____

3. How much difficulty did you have in the last 6 months taking your FK506 (Prograf) as prescribed?

   _____ I am not on Prograf
   _____ no difficulty
   _____ a little difficulty
   _____ moderate difficulty
   _____ a lot of difficulty

   If you did have difficulty, please state why:

   _____

1

4. How much difficulty did you have in the last 6 months taking your mycophenolate mofetil (Cellcept) as prescribed?

    _____ I am not on Cellcept
    _____ no difficulty
    _____ a little difficulty
    _____ moderate difficulty
    _____ a lot of difficulty

    If you did have difficulty, please state why:

    _____

5. How much difficulty did you have in the last 6 months taking your azathioprine (Imuran) as prescribed?

    _____ I am not on Imuran
    _____ no difficulty
    _____ a little difficulty
    _____ moderate difficulty
    _____ a lot of difficulty

    If you did have difficulty, please state why:

    _____

6. How much difficulty did you have in the last 6 months taking your prednisone as prescribed?

    _____ I am not on prednisone
    _____ no difficulty
    _____ a little difficulty
    _____ moderate difficulty
    _____ a lot of difficulty

    If you did have difficulty, please state why:

    _____

7. How much difficulty did you have in the last 6 months taking ANY OTHER ANTI-REJECTION MEDICATION that you're on?

    _____ I am not on any other anti-rejection medication
    _____ no difficulty
    _____ a little difficulty
    _____ moderate difficulty
    _____ a lot of difficulty

    Please list the name of this other anti-rejection medication:

    _____

    If you did have difficulty taking the medication you listed above, please state why:

    _____

8. How much difficulty did you have in the last 6 months taking all your other medications as prescribed (such as water pill or blood pressure pill)?

_____ no difficulty
_____ a little difficulty
_____ moderate difficulty
_____ a lot of difficulty

If you did have difficulty, please state why:
_____

9. How much difficulty did you have in the last 6 months following your diet as prescribed?

_____ I am not on a special diet
_____ no difficulty
_____ a little difficulty
_____ moderate difficulty
_____ a lot of difficulty

If you did have difficulty, please state why:
_____

10. How much difficulty did you have in the last 6 months following a scheduled exercise program?

_____ I am not on a scheduled exercise program
_____ no difficulty
_____ a little difficulty
_____ moderate difficulty
_____ a lot of difficulty

If you did have difficulty, please state why:
_____

11. How much difficulty did you have in the last 6 months staying away from smoking? (**Note:** If you smoked in the past, do not respond, "I am not a smoker", check a response regarding how difficult it has been to stay away from smoking).

_____ I am not a smoker
_____ no difficulty
_____ a little difficulty
_____ moderate difficulty
_____ a lot of difficulty

If you did have difficulty, please state why:
_____

3

12. How much difficulty did you have in the last 6 months taking your vital signs as scheduled (for example: your blood pressure)?

_____ I did not have to take my vital signs
_____ no difficulty
_____ a little difficulty
_____ moderate difficulty
_____ a lot of difficulty

If you did have difficulty, please state why:

_____

13. How much difficulty did you have in the last 6 months calling your doctor or nurse whenever you had problems?

_____ I did not have any problems to call about
_____ no difficulty
_____ a little difficulty
_____ moderate difficulty
_____ a lot of difficulty

If you did have difficulty, please state why:

_____

14. How much difficulty did you have in the last 6 months coming into the clinic for your check-ups as scheduled?

_____ I did not have any clinic visits scheduled
_____ no difficulty
_____ a little difficulty
_____ moderate difficulty
_____ a lot of difficulty

If you did have difficulty, please state why:

_____

15. How much difficulty did you have in the last 6 months coming in for your tests as scheduled?

_____ I did not have any tests scheduled
_____ no difficulty
_____ a little difficulty
_____ moderate difficulty
_____ a lot of difficulty

If you did have difficulty, please state why:

_____

4

PART B

PLEASE PLACE A "CHECKMARK" NEXT TO THE RESPONSE THAT BEST DESCRIBES HOW MUCH YOU ACTUALLY FOLLOWED YOUR HEART TRANSPLANT REGIMEN <u>IN THE LAST 6 MONTHS.</u>

1. How much of the time during the last 6 months did you take all your anti-rejection medications in general?

_____ all of the time
_____ most of the time
_____ some of the time
_____ hardly ever

2. How much of the time during the last 6 months did you take your cyclosporine (<u>Sandimmune</u> or <u>Neoral</u> or <u>SangCya</u>) as prescribed?

_____ I am not on cyclosporine
_____ all of the time
_____ most of the time
_____ some of the time
_____ hardly ever

3. How much of the time during the last 6 months did you take your mycophenolate mofetil (<u>Cellcept</u>) as prescribed?

_____ I am not on Cellcept
_____ all of the time
_____ most of the time
_____ some of the time
_____ hardly ever

4. How much of the time during the last 6 months did you take your FK506 (<u>Prograf</u>) as prescribed?

_____ I am not on Prograf
_____ all of the time
_____ most of the time
_____ some of the time
_____ hardly ever

5. How much of the time during the last 6 months did you take your azathioprine (<u>Imuran</u>) azathioprine as prescribed?

_____ I am not on Imuran
_____ all of the time
_____ most of the time
_____ some of the time
_____ hardly ever

5

6. How much of the time during the last 6 months did you take your <u>prednisone</u> as prescribed?

  _____ I am not on prednisone
  _____ all of the time
  _____ most of the time
  _____ some of the time
  _____ hardly ever

7. How much of the time during the last 6 months did you take the OTHER ANTI-REJECTION MEDICATION that you listed on Question #7 in Part A of this form?

  _____ I am not on any other anti-rejection medication
  _____ all of the time
  _____ most of the time
  _____ some of the time
  _____ hardly ever

8. How much of the time during the last 6 months did you take all of your other medications as prescribed (such as water pill or blood pressure pill)?

  _____ all of the time
  _____ most of the time
  _____ some of the time
  _____ hardly ever

9. How much of the time during the last 6 months did you follow your diet as prescribed?

  _____ I am not on a special diet
  _____ all of the time
  _____ most of the time
  _____ some of the time
  _____ hardly ever

10. How much of the time during the last 6 months did you follow a scheduled exercise program?

  _____ I am not on a scheduled exercise program
  _____ all of the time
  _____ most of the time
  _____ some of the time
  _____ hardly ever

6

11. How much of the time during the last 6 months did you stay away from smoking? (**NOTE**: if you smoked in the past, do not respond "I am not a smoker", check a response regarding how much you actually stayed away from smoking).

_____ I am not a smoker
_____ all of the time
_____ most of the time
_____ some of the time
_____ hardly ever

12. How much of the time during the last 6 months did you take your vital signs as scheduled (for example: your blood pressure)?

_____ I did not have to take my vital signs
_____ all of the time
_____ most of the time
_____ some of the time
_____ hardly ever

13. How much of the time during the last 6 months did you call your doctor or nurse whenever you had problems?

_____ I did not have any problems to call about
_____ all of the time
_____ most of the time
_____ some of the time
_____ hardly ever

14. How much of the time during the last 6 months did you come into the clinic for your check-ups as scheduled?

_____ I did not have any clinic visits scheduled
_____ all of the time
_____ most of the time
_____ some of the time
_____ hardly ever

15. How much of the time during the last 6 months did you come in for your tests as scheduled?

_____ I did not have any tests scheduled
_____ all of the time
_____ most of the time
_____ some of the time
_____ hardly ever

7

121

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JALOWIEC COPING SCALE

</div>

This questionnaire is about how you cope with stress and tension, and what you do to handle stressful situations. In particular, we are interested in how you have coped with the stress of:

RECOVERING FROM HEART TRANSPLANT SURGERY <u>IN THE LAST SIX MONTHS</u>

This questionnaire lists many different ways of coping with stress. Some people use a lot of different coping methods; some people use only a few.

You will be asked two questions about each different way of coping with stress:

Part A

How <u>often</u> have you used that coping method to handle the stress listed above?

For each coping method listed, circle one number in Part A to show how often you have used that method to cope with the stress listed above. The meaning of the numbers in Part A is as follows:

0	=	never used
1	=	seldom used
2	=	sometimes used
3	=	often used

Part B

If you have used that coping method, how <u>helpful</u> was it in dealing with that stress?

For each coping method that you have used, circle a number in Part B to show how helpful that method was in coping with the stress listed above. The meaning of the numbers in Part B is as follows:

0	=	not helpful
1	=	slightly helpful
2	=	fairly helpful
3	=	very helpful

If you did not use a particular coping method (you circled "0 = never used"), then do not circle any number in Part B for that coping method.

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1

COPING METHODS	Part A How often have you used each coping method?				Part B If you have used that coping method, how helpful was it?			
	Never Used	Seldom Used	Sometimes Used	Often Used	Not Helpful	Slightly Helpful	Fairly Helpful	Very Helpful
1. Worried about the problem	0	1	2	3	0	1	2	3
2. Hoped that things would get better	0	1	2	3	0	1	2	3
3. Ate or smoked more than usual	0	1	2	3	0	1	2	3
4. Thought out different ways to handle the situation	0	1	2	3	0	1	2	3
5. Told yourself that things could be much worse	0	1	2	3	0	1	2	3
6. Exercised or did some physical activity	0	1	2	3	0	1	2	3
7. Tried to get away from the problem for a while	0	1	2	3	0	1	2	3
8. Got mad and let off steam	0	1	2	3	0	1	2	3
9. Expected the worst that could happen	0	1	2	3	0	1	2	3
10. Tried to put the problem out of your mind and think of something else	0	1	2	3	0	1	2	3
11. Talked the problem over with family or friends	0	1	2	3	0	1	2	3
12. Accepted the situation because very little could be done	0	1	2	3	0	1	2	3
13. Tried to look at the problem objectively and see all sides	0	1	2	3	0	1	2	3
14. Daydreamed about a better life	0	1	2	3	0	1	2	3
15. Talked the problem over with a professional person (such as a doctor, nurse, minister, teacher, counselor)	0	1	2	3	0	1	2	3
16. Tried to keep the situation under control	0	1	2	3	0	1	2	3
17. Prayed or put your trust in God	0	1	2	3	0	1	2	3
18. Tried to get out of the situation	0	1	2	3	0	1	2	3
19. Kept your feelings to yourself	0	1	2	3	0	1	2	3
20. Told yourself that the problem was someone else's fault	0	1	2	3	0	1	2	3
21. Waited to see what would happen	0	1	2	3	0	1	2	3
22. Wanted to be alone to think things out	0	1	2	3	0	1	2	3
23. Resigned yourself to the situation because things looked hopeless	0	1	2	3	0	1	2	3
24. Took out your tensions on someone else	0	1	2	3	0	1	2	3
25. Tried to change the situation	0	1	2	3	0	1	2	3
26. Used relaxation techniques	0	1	2	3	0	1	2	3

2

COPING METHODS	Part A How often have you used each coping method?				Part B If you have used that coping method, how helpful was it?			
	Never Used	Seldom Used	Sometimes Used	Often Used	Not Helpful	Slightly Helpful	Fairly Helpful	Very Helpful
27. Tried to find out more about the problem	0	1	2	3	0	1	2	3
28. Slept more than usual	0	1	2	3	0	1	2	3
29. Tried to handle things one step at a time	0	1	2	3	0	1	2	3
30. Tried to keep your life as normal as possible & not let the problem interfere	0	1	2	3	0	1	2	3
31. Thought about how you had handled other problems in the past	0	1	2	3	0	1	2	3
32. Told yourself not to worry because everything would work out fine	0	1	2	3	0	1	2	3
33. Tried to work out a compromise	0	1	2	3	0	1	2	3
34. Took a drink to make yourself feel better	0	1	2	3	0	1	2	3
35. Let time take care of the problem	0	1	2	3	0	1	2	3
36. Tried to distract yourself by doing something that you enjoy	0	1	2	3	0	1	2	3
37. Told yourself that you could handle anything no matter how hard	0	1	2	3	0	1	2	3
38. Set up a plan of action	0	1	2	3	0	1	2	3
39. Tried to keep a sense of humor	0	1	2	3	0	1	2	3
40. Put off facing up to the problem	0	1	2	3	0	1	2	3
41. Tried to keep your feelings under control	0	1	2	3	0	1	2	3
42. Talked the problem over with someone who had been in a similar situation	0	1	2	3	0	1	2	3
43. Practiced in your mind what had to be done	0	1	2	3	0	1	2	3
44. Tried to keep busy	0	1	2	3	0	1	2	3
45. Learned something new in order to deal with the problem	0	1	2	3	0	1	2	3
46. Did something impulsive or risky that you would not usually do	0	1	2	3	0	1	2	3
47. Thought about the good things in your life	0	1	2	3	0	1	2	3
48. Tried to ignore or avoid the problem	0	1	2	3	0	1	2	3
49. Compared yourself with other people who were in the same situation	0	1	2	3	0	1	2	3
50. Tried to think positively	0	1	2	3	0	1	2	3

3

COPING METHODS	Part A How often have you used each coping method?				Part B If you have used that coping method, how helpful was it?			
	Never Used	Seldom Used	Sometimes Used	Often Used	Not Helpful	Slightly Helpful	Fairly Helpful	Very Helpful
51. Blamed yourself for getting into such a situation	0	1	2	3	0	1	2	3
52. Preferred to work things out yourself	0	1	2	3	0	1	2	3
53. Took medications to reduce tension	0	1	2	3	0	1	2	3
54. Tried to see the good side of the situation	0	1	2	3	0	1	2	3
55. Told yourself that this problem was really not that important	0	1	2	3	0	1	2	3
56. Avoided being with people	0	1	2	3	0	1	2	3
57. Tried to improve yourself in some way so you could handle the situation better	0	1	2	3	0	1	2	3
58. Wished that the problem would go away	0	1	2	3	0	1	2	3
59. Depended on others to help you out	0	1	2	3	0	1	2	3
60. Told yourself that you were just having some bad luck	0	1	2	3	0	1	2	3

If there are any other things you did to handle the stress mentioned at the beginning, that are not on this list, please write those coping methods in the spaces below. Then circle how often you have used each coping method, and how helpful each coping method has been.

61.	1	2	3	0	1	2	3
62.	1	2	3	0	1	2	3
63.	1	2	3	0	1	2	3

4

SOCIAL SUPPORT INDEX

The following questions ask about the kinds of help you get from other people, how satisfied you are with that help, and about your social activities and family relationships. Please answer the questions <u>in relation to the last 6 months</u>.

PART A

1. Check all those people who do chores around the house (or yard) for you when you're not feeling well or when you're in the hospital:
   _____ spouse (or partner)
   _____ family member (such as child, parent, brother, sister)
   _____ relative (such as aunt, uncle, cousin, in-law)
   _____ person from work or school
   _____ spiritual advisor or person from church
   _____ other transplant patients or their families
   _____ friend or neighbor
   _____ professional person (such as doctor, nurse, social worker, therapist)
   _____ paid helper
   _____ no one helps me even though I need help in this area
   _____ I don't need any help in this area right now

   If you do get help in this area, how satisfied are you with the help?
   _____ very satisfied
   _____ fairly satisfied
   _____ somewhat dissatisfied
   _____ very dissatisfied

2. Check all those people who take care of your children (or of sick or elderly family members) when you're not feeling well or when you're in the hospital:
   _____ spouse (or partner)
   _____ family member (such as child, parent, brother, sister)
   _____ relative (such as aunt, uncle, cousin, in-law)
   _____ person from work or school
   _____ spiritual advisor or person from church
   _____ other transplant patients or their families
   _____ friend or neighbor
   _____ professional person (such as doctor, nurse, social worker, therapist)
   _____ paid helper
   _____ no one helps me even though I need help in this area
   _____ I don't need any help in this area right now

   If you do get help in this area, how satisfied are you with the help?
   _____ very satisfied
   _____ fairly satisfied
   _____ somewhat dissatisfied
   _____ very dissatisfied

1

3. Check all those people who help you with your personal care at home if you're not feeling well (as helping with bathing):
    _____ spouse (or partner)
    _____ family member (such as child, parent, brother, sister)
    _____ relative (such as aunt, uncle, cousin, in-law)
    _____ person from work or school
    _____ spiritual advisor or person from church
    _____ other transplant patients or their families
    _____ friend or neighbor
    _____ professional person (such as doctor, nurse, social worker, therapist)
    _____ paid helper
    _____ no one helps me even though I need help in this area
    _____ I don't need any help in this area right now

    If you do get help in this area, how satisfied are you with the help?
    _____ very satisfied
    _____ fairly satisfied
    _____ somewhat dissatisfied
    _____ very dissatisfied

4. Check all those people you can count on if you need a ride to the doctor or hospital:
    _____ spouse (or partner)
    _____ family member (such as child, parent, brother, sister)
    _____ relative (such as aunt, uncle, cousin, in-law)
    _____ person from work or school
    _____ spiritual advisor or person from church
    _____ other transplant patients or their families
    _____ friend or neighbor
    _____ professional person (such as doctor, nurse, social worker, therapist)
    _____ paid helper
    _____ no one helps me even though I need help in this area
    _____ I don't need any help in this area right now

    If you do get help in this area, how satisfied are you with the help?
    _____ very satisfied
    _____ fairly satisfied
    _____ somewhat dissatisfied
    _____ very dissatisfied

2

5. Check all those people who will help you with money if you need it:
_____ spouse (or partner)
_____ family member (such as child, parent, brother, sister)
_____ relative (such as aunt, uncle, cousin, in-law)
_____ person from work or school
_____ spiritual advisor or person from church
_____ other transplant patients or their families
_____ friend or neighbor
_____ professional person (such as doctor, nurse, social worker, therapist)
_____ paid helper
_____ no one helps me even though I need help in this area
_____ I don't need any help in this area right now

If you do get help in this area, how satisfied are you with the help?
_____ very satisfied
_____ fairly satisfied
_____ somewhat dissatisfied
_____ very dissatisfied

6. Check all those people who help you by talking with you about your problems:
_____ spouse (or partner)
_____ family member (such as child, parent, brother, sister)
_____ relative (such as aunt, uncle, cousin, in-law)
_____ person from work or school
_____ spiritual advisor or person from church
_____ other transplant patients or their families
_____ friend or neighbor
_____ professional person (such as doctor, nurse, social worker, therapist)
_____ paid helper
_____ no one helps me even though I need help in this area
_____ I don't need any help in this area right now

If you do get help in this area, how satisfied are you with the help?
_____ very satisfied
_____ fairly satisfied
_____ somewhat dissatisfied
_____ very dissatisfied

3

7. Check all those people you can count on in an emergency:
    _____ spouse (or partner)
    _____ family member (such as child, parent, brother, sister)
    _____ relative (such as aunt, uncle, cousin, in-law)
    _____ person from work or school
    _____ spiritual advisor or person from church
    _____ other transplant patients or their families
    _____ friend or neighbor
    _____ professional person (such as doctor, nurse, social worker, therapist)
    _____ paid helper
    _____ no one helps me even though I need help in this area
    _____ I don't need any help in this area right now

    If you do get help in this area, how satisfied are you with the help?
    _____ very satisfied
    _____ fairly satisfied
    _____ somewhat dissatisfied
    _____ very dissatisfied

8. Check all those people who go for groceries or run errands for you when you're not feeling well or when you're in the hospital:
    _____ spouse (or partner)
    _____ family member (such as child, parent, brother, sister)
    _____ relative (such as aunt, uncle, cousin, in-law)
    _____ person from work or school
    _____ spiritual advisor or person from church
    _____ other transplant patients or their families
    _____ friend or neighbor
    _____ professional person (such as doctor, nurse, social worker, therapist)
    _____ paid helper
    _____ no one helps me even though I need help in this area
    _____ I don't need any help in this area right now

    If you do get help in this area, how satisfied are you with the help?
    _____ very satisfied
    _____ fairly satisfied
    _____ somewhat dissatisfied
    _____ very dissatisfied

4

9. Check all those people who help you take your medications when you're at home:
   _____ spouse (or partner)
   _____ family member (such as child, parent, brother, sister)
   _____ relative (such as aunt, uncle, cousin, in-law)
   _____ person from work or school
   _____ spiritual advisor or person from church
   _____ other transplant patients or their families
   _____ friend or neighbor
   _____ professional person (such as doctor, nurse, social worker, therapist)
   _____ paid helper
   _____ no one helps me even though I need help in this area
   _____ I don't need any help in this area right now

   If you do get help in this area, how satisfied are you with the help?
   _____ very satisfied
   _____ fairly satisfied
   _____ somewhat dissatisfied
   _____ very dissatisfied

10. Check all those people who help you with information or advice on financial, legal, or insurance matters:
    _____ spouse (or partner)
    _____ family member (such as child, parent, brother, sister)
    _____ relative (such as aunt, uncle, cousin, in-law)
    _____ person from work or school
    _____ spiritual advisor or person from church
    _____ other transplant patients or their families
    _____ friend or neighbor
    _____ professional person (such as doctor, nurse, social worker, therapist)
    _____ paid helper
    _____ no one helps me even though I need help in this area
    _____ I don't need any help in this area right now

    If you do get help in this area, how satisfied are you with the help?
    _____ very satisfied
    _____ fairly satisfied
    _____ somewhat dissatisfied
    _____ very dissatisfied

5

11. Check all those people who help you keep track of your health when you're at home (as by Helping with your vital signs, or watching for signs of heart failure, or signs of infection or rejection):
_____ spouse (or partner)
_____ family member (such as child, parent, brother, sister)
_____ relative (such as aunt, uncle, cousin, in-law)
_____ person from work or school
_____ spiritual advisor or person from church
_____ other transplant patients or their families
_____ friend or neighbor
_____ professional person (such as doctor, nurse, social worker, therapist)
_____ paid helper
_____ no one helps me even though I need help in this area
_____ I don't need any help in this area right now

If you do get help in this area, how satisfied are you with the help?
_____ very satisfied
_____ fairly satisfied
_____ somewhat dissatisfied
_____ very dissatisfied

12. Check all those people you feel you can confide in when you want to talk about intimate personal concerns:
_____ spouse (or partner)
_____ family member (such as child, parent, brother, sister)
_____ relative (such as aunt, uncle, cousin, in-law)
_____ person from work or school
_____ spiritual advisor or person from church
_____ other transplant patients or their families
_____ friend or neighbor
_____ professional person (such as doctor, nurse, social worker, therapist)
_____ paid helper
_____ no one helps me even though I need help in this area
_____ I don't need any help in this area right now

If you do get help in this area, how satisfied are you with the help?
_____ very satisfied
_____ fairly satisfied
_____ somewhat dissatisfied
_____ very dissatisfied

6

13. Check all those people who help you stick to your transplant program when you're at home:
_____ spouse (or partner)
_____ family member (such as child, parent, brother, sister)
_____ relative (such as aunt, uncle, cousin, in-law)
_____ person from work or school
_____ spiritual advisor or person from church
_____ other transplant patients or their families
_____ friend or neighbor
_____ professional person (such as doctor, nurse, social worker, therapist)
_____ paid helper
_____ no one helps me even though I need help in this area
_____ I don't need any help in this area right now

If you do get help in this area, how satisfied are you with the help?
_____ very satisfied
_____ fairly satisfied
_____ somewhat dissatisfied
_____ very dissatisfied

14. Check all those people who help you feel good about yourself:
_____ spouse (or partner)
_____ family member (such as child, parent, brother, sister)
_____ relative (such as aunt, uncle, cousin, in-law)
_____ person from work or school
_____ spiritual advisor or person from church
_____ other transplant patients or their families
_____ friend or neighbor
_____ professional person (such as doctor, nurse, social worker, therapist)
_____ paid helper
_____ no one helps me even though I need help in this area
_____ I don't need any help in this area right now

If you do get help in this area, how satisfied are you with the help?
_____ very satisfied
_____ fairly satisfied
_____ somewhat dissatisfied
_____ very dissatisfied

7

15. Check all those people who give you encouragement to keep on going when things are rough:
_____ spouse (or partner)
_____ family member (such as child, parent, brother, sister)
_____ relative (such as aunt, uncle, cousin, in-law)
_____ person from work or school
_____ spiritual advisor or person from church
_____ other transplant patients or their families
_____ friend or neighbor
_____ professional person (such as doctor, nurse, social worker, therapist)
_____ paid helper
_____ no one helps me even though I need help in this area
_____ I don't need any help in this area right now

If you do get help in this area, how satisfied are you with the help?
_____ very satisfied
_____ fairly satisfied
_____ somewhat dissatisfied
_____ very dissatisfied

PART B

1. How often do you attend the Heart Transplant Support Group?
_____ every month
_____ almost every month
_____ every few months
_____ once in a great while
_____ have only attended once
_____ have never attended

2. How often do you attend religious services?
_____ once a week or more
_____ once or twice a month
_____ every few months
_____ once or twice a year
_____ have not attended in many years
_____ never attended

3. How good do you feel your relationship has been with the following family members during the last 6 months?

	Very Good	Fairly Good	OK	Fairly Bad	Very Bad
spouse (partner)	____	____	____	____	____
other members of your family	____	____	____	____	____

4. How many social, community, or family activities have you participated in during the last 6 months?

_____

8

SICKNESS IMPACT PROFILE

INTRODUCTION

PLEASE READ THE ENTIRE INTRODUCTION BEFORE YOU READ THE QUESTIONNAIRE. IT IS VERY IMPORTANT THAT EVERYONE TAKING THE QUESTIONNAIRE FOLLOWS THE SAME INSTRUCTIONS.

You have certain activities that you do in carrying on your life. Sometimes you do all of these activities. Other times, because of your state of health, you don't do these activities in the usual way: you may cut some out; you may do some for shorter lengths of time; you may do some in different ways. These changes in your activities might be recent or longstanding. We are interested in learning about **any** changes that described you during the past 1 month and were related to your state of health.

The questionnaire lists statements that people have told us describe them when they are not completely well. Whether or not you consider yourself sick, there may be some statements that will stand out because they described **you** during the past 1 month and were related to your state of health. As you read the questionnaire, think of **yourself during the past 1 month**. When you read a statement that you are sure described you and was related to your **health**, check YES on the line to the right of the statement. For example:

	YES	NO
I am not driving my car	√	

If you have not been driving for some time because of your health, and have still not driven during the past 1 month, you should respond **YES** to this statement.

On the other hand, if you never drive or were not driving during the past 1 month because your car was being repaired, the statement, "I am not driving my car" was not related to your health and you should check **NO** on the line to the right of the statement. If you simply have been driving less, or were driving shorter distances, and feel that the statement only partially describes you, check **NO**. For example:

	YES	NO
I am not driving my car		√

Remember that we want you to check this statement **only** if you are **sure** it described you during the past 1 month and was related to your state of health.

SICKNESS IMPACT PROFILE

PLEASE CHECK YES <u>ONLY</u> FOR THOSE STATEMENTS THAT YOU ARE SURE DESCRIBED YOU DURING THE PAST 1 MONTH AND WERE RELATED TO YOUR STATE OF HEALTH.

		YES	NO
1.	I spend much of the day lying down in order to rest		
2.	I sit during much of the day		
3.	I am sleeping or dozing most of the time – day and night		
4.	I lie down more often during the day in order to rest		
5.	I sit around half-asleep		
6.	I sleep less at night, for example, wake up too early, don't fall asleep for a long time, awaken frequently		
7.	I sleep or nap more during the day		
8.	I say how bad or useless I am, for example, that I am a burden on others		
9.	I laugh or cry suddenly		
10.	I often moan and groan in pain or discomfort		
11.	I have attempted suicide		
12.	I act nervous or restless		
13.	I keep rubbing or holding areas of my body that hurt or are uncomfortable		
14.	I act irritable and impatient with myself, for example, talk badly about myself, swear at myself, blame myself for things that happen		
15.	I talk about the future in a hopeless way		
16.	I get sudden frights		
17.	I make difficult moves with help, for example, getting into or out of cars, bathtubs		
18.	I do not move into or out of bed or chair by myself but am moved by a person or mechanical aid		
19.	I stand only for short periods of time		
20.	I do not maintain balance		
21.	I move my hands or fingers wit some limitation or difficulty		
22.	I stand up only with someone's help		
23.	I kneel, stoop, or bend down only by holding on to something		
24.	I kneel, stoop, or bend down only by holding on to something		

1

PLEASE CHECK YES _ONLY_ FOR THOSE STATEMENTS THAT YOU ARE SURE DESCRIBED YOU DURING THE PAST 1 MONTH AND WERE RELATED TO YOUR STATE OF HEALTH.

		YES	NO
25.	I am very clumsy in body movements	___	___
26.	I get in and out of bed or chairs by grasping something for support or using a cane or walker	___	___
27.	I stay lying down most of the time	___	___
28.	I change position frequently	___	___
29.	I hold on to something to move myself around in bed	___	___
30.	I do not bathe myself completely, for example, require assistance with bathing	___	___
31.	I do not bathe myself at all, but am bathed by someone else	___	___
32.	I use a bedpan with assistance	___	___
33.	I have trouble getting shoes, or stockings on	___	___
34.	I do not have control of my bladder	___	___
35.	I do not fasten my clothing, for example, require assistance with buttons, zippers, shoelaces	___	___
36.	I spend most of the time partly undressed or in pajamas	___	___
37.	I do not have control of my bowels	___	___
38.	I dress myself, but do so very slowly	___	___
39.	I get dressed only with someone's help	___	___
40.	I do work around the house only for short periods of time or rest often	___	___
41.	I am doing _less_ of the regular daily work around the house than I would usually do	___	___
42.	I am not doing _any_ of the regular daily work around the house that I would usually do	___	___
43.	I am not doing _any_ of the maintenance or repair work that I would usually do in my home or yard	___	___
44.	I am not doing _any_ of the shopping that I would usually do	___	___
45.	I am not doing _any_ of the house cleaning that I would usually do	___	___
46.	I have difficulty doing handwork, for example, turning faucets, using kitchen gadgets, sewing, carpentry	___	___
47.	I am not doing _any_ of the clothes washing that I would usually do	___	___
48.	I am not doing heavy work around the house	___	___
49.	I have given up taking care of personal or household business affairs, for example, paying bills, banking, working on budget	___	___

2

***PLEASE CHECK YES <u>ONLY</u> FOR THOSE STATEMENTS THAT YOU ARE SURE DESCRIBED
YOU DURING THE PAST 1 MONTH AND WERE RELATED TO YOUR STATE OF HEALTH.***

		YES	NO
50.	I am getting around only within one building	___	___
51.	I stay within one room	___	___
52.	I am staying in bed more	___	___
53.	I am staying in bed most of the time	___	___
54.	I am not now using public transportation	___	___
55.	I stay home most of the time	___	___
56.	I am going to places with restrooms nearby	___	___
57.	I am not going into town	___	___
58.	I stay away from home only for brief periods of time	___	___
59.	I do not get around in the dark or in unlit places without someone's help	___	___
60.	I am going out less to visit people	___	___
61.	I am not going out to visit people at all	___	___
62.	I show less interest in other people's problems, for example, don't listen when they tell me about their problems, don't offer to help	___	___
63.	I often act irritable toward those around me, for example, snap at people, give sharp answers, criticize easily	___	___
64.	I show less affection	___	___
65.	I am doing fewer social activities with groups of people	___	___
66.	I am cutting down the length of visits with friends	___	___
67.	I am avoiding social visits from others	___	___
68.	My sexual activity is decreased	___	___
69.	I often express concern over what might be happening to my health	___	___
70.	I talk less with those around me	___	___
71.	I make many demands, for example, insist that people do things for me, tell them how to do things	___	___
72.	I stay alone much of the time	___	___
73.	I act disagreeable to family members, for example, I act spiteful, I am stubborn	___	___
74.	I have frequent outbursts of anger at family members, for example, strike at them, scream, throw things at them	___	___
75.	I isolate myself as much as I can from the rest of the family	___	___
76.	I am paying less attention to the children	___	___

3

		YES	NO
77.	I refuse contact with family members, for example, turn away from them	_____	____
78.	I am not doing the things I usually do to take care of my children or family	_____	____
79.	I am not joking with family members as I usually do	_____	____
80.	I walk shorter distances or stop to rest often	_____	____
81.	I do not walk up or down hills	_____	____
82.	I use stairs only with mechanical support, for example, handrail, cane, crutches	_____	____
83.	I walk up or down stairs only with assistance from someone else	_____	____
84.	I get around in a wheelchair	_____	____
85.	I do not walk at all	_____	____
86.	I walk by myself, but with some difficulty, for example, limp, wobble, stumble, have stiff legs	_____	____
87.	I walk only with help from someone	_____	____
88.	I go up and down stairs more slowly, for example, one step at a time, stop often	_____	____
89.	I do not use stairs at all	_____	____
90.	I get around only by using a walker, crutches, cane, walls, or furniture	_____	____
91.	I walk more slowly	_____	____
92.	I am confused and start several actions at a time	_____	____
93.	I have more minor accidents, for example, drop things, trip and fall, bump into things	_____	____
94.	I react slowly to things that are said or done	_____	____
95.	I do not finish things I start	_____	____
96.	I have difficulty reasoning and solving problems, for example, making decisions, learning new things	_____	____
97.	I sometimes behave as if I were confused or disoriented in place or time, for example, where I am, who is around, directions, what day it is	_____	____
98.	I forget a lot, for example, things that happened recently, where I put things, appointments	_____	____
99.	I do not keep my attention on any activity for long	_____	____
100.	I make more mistakes than usual	_____	____
101.	I have difficulty doing activities involving concentration and thinking	_____	____
102.	I am having trouble writing or typing	_____	____

4

PLEASE CHECK YES ONLY FOR THOSE STATEMENTS THAT YOU ARE SURE DESCRIBED YOU DURING THE PAST 1 MONTH AND WERE RELATED TO YOUR STATE OF HEALTH.

		YES	NO
103.	I communicate mostly by gestures, for example, moving head, pointing, sign language	_____	_____
104.	My speech is understood only by a few people who know me well	_____	_____
105.	I often lose control of my voice when I talk, for example, my voice gets louder or softer, trembles, changes unexpectedly	_____	_____
106.	I don't write except to sign my name	_____	_____
107.	I carry on a conversation only when very close to the other person or looking at him	_____	_____
108.	I have difficulty speaking, for example, get stuck, stutter, stammer, slur my words	_____	_____
109.	I am understood with difficulty	_____	_____
110.	I do not speak clearly when I am under stress	_____	_____
111.	I do my hobbies and recreation for shorter periods of time	_____	_____
112.	I am going out for entertainment less often	_____	_____
113.	I am cutting down on some of my usual inactive recreation and pastimes, for example, watching TV, playing cards, reading	_____	_____
114.	I am not doing any of my usual inactive recreation and pastimes, for example, watching TV, playing cards, reading	_____	_____
115.	I am doing more inactive pastimes in place of my other usual activities	_____	_____
116.	I am doing fewer community activities	_____	_____
117.	I am cutting down on some of my usual physical recreation or activities	_____	_____
118.	I am not doing any of my usual physical recreation or activities	_____	_____
119.	I am eating much less than usual	_____	_____
120.	I feed myself, but only by using specially prepared food or utensils	_____	_____
121.	I am eating special or different food, for example, soft food, bland diet, low-salt, low-fat, low sugar diet	_____	_____
122.	I eat no food at all but am taking fluids	_____	_____
123.	I just pick or nibble at my food	_____	_____
124.	I am drinking less fluids	_____	_____
125.	I feed myself with help from someone else	_____	_____
126.	I do not feed myself at all, but must be fed	_____	_____
127.	I am eating no food at all, nutrition is taken through tubes or intravenous fluids	_____	_____

5

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PLEASE CHECK YES <u>ONLY</u> FOR THOSE STATEMENTS THAT YOU ARE SURE DESCRIBED YOU DURING THE PAST 1 MONTH AND WERE RELATED TO YOUR STATE OF HEALTH.

		YES	NO
128.	I am not working at all	____	____

<u>IF YOU ARE NOT WORKING</u>, PLEASE SKIP THE REST OF THIS PAGE.

<u>IF YOU ARE WORKING</u>, CONSIDER THE WORK YOU DO AND CHECK YES <u>ONLY</u> FOR THOSE STATEMENTS THAT YOU ARE <u>SURE</u> DESCRIBED YOU DURING THE PAST 1 MONTH AND WERE RELATED TO YOUR STATE OF HEALTH.

		YES	NO
129.	I am doing part of my job at home	____	____
130.	I am not accomplishing as much as usual at work	____	____
131.	I often act irritable toward my work associates, for example, snap at them, give sharp answers, criticize easily	____	____
132.	I am working shorter hours	____	____
133.	I am doing only light work	____	____
134.	I work only for short periods of time or take frequent rests	____	____
135.	I am working at my usual job, but with some changes, for example, using different tools or special aids, trading some tasks with other workers	____	____
136.	I do not do my job as carefully and accurately as usual	____	____

6

THE EMOTION SCALE

This scale consists of a number of words and phrases that describe different feelings and emotions. Read each item and then mark the appropriate answer in the space next to that word. Indicate <u>to what extent you have felt this way during the past 1 month</u>. Use the following scale to record your answers:

1 Very slightly or not at all	2 a little	3 moderately	4 quite a bit	5 extremely

_____ cheerful

_____ disgusted

_____ attentive

_____ sluggish

_____ daring

_____ strong

_____ scornful

_____ relaxed

_____ irritable

_____ delighted

_____ inspired

_____ fearless

_____ disgusted with myself

_____ sad

_____ calm

_____ afraid

_____ tired

_____ shaky

_____ happy

_____ alone

_____ alert

_____ upset

_____ angry

_____ bold

_____ blue

_____ active

_____ guilty

_____ joyful

_____ nervous

_____ lonely

_____ sleepy

_____ excited

_____ hostile

_____ proud

_____ jittery

_____ lively

_____ ashamed

_____ at ease

_____ scared

_____ drowsy

_____ angry with myself

_____ enthusiastic

_____ downhearted

_____ distressed

_____ deserving blame

_____ determined

_____ frightened

_____ interested

_____ loathing

_____ confident

_____ energetic

_____ dissatisfied with myself

CDS

(Hare / Davis)

This questionnaire consists of a number of statements about the way you have felt ***during the past 1 month***.

Next to each statement there is a rating scale from 1 to 7 and words to indicate how much you agree or disagree with the statement. Please read each statement carefully, read the words at each end of the rating scale, and circle one of the numbers on the scale to indicate how much you agree or disagree with the statement.

A score of a 4 would indicate that you neither agree nor disagree with the statement, a score of 1 that you strongly disagree, and a score of 7 that you strongly agree.

EXAMPLE

1. I have dropped many of my interests and activities...

    1   (2)   3   4   5   6   7
None dropped   All dropped

This indicates that you quite strongly disagree with the statement as you have not dropped many of your interests and activities.

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1.	I have dropped many of my interests and activities...	1 None dropped	2	3	4	5	6	7 All dropped
2.	My concentration is as good as it ever was...	1 Very poor concentration	2	3	4	5	6	7 Excellent concentration
3.	I can't be bothered doing anything much...	1 Keen to do things	2	3	4	5	6	7 Can't be bothered
4.	I get pleasure from life at present...	1 No pleasure	2	3	4	5	6	7 Great pleasure
5.	I am concerned about the uncertainty of my health...	1 Not concerned	2	3	4	5	6	7 Very concerned
6.	I may not recover properly...	1 Will recover completely	2	3	4	5	6	7 Will not recover
7.	My sleep is restless and disturbed...	1 Not restless	2	3	4	5	6	7 Very restless
8.	I am not the person I used to be...	1 Just the same	2	3	4	5	6	7 Completely different
9.	I wake up in the early hours of the morning and cannot get back to sleep...	1 Never wake	2	3	4	5	6	7 Always wake
10.	I feel like I'm living on borrowed time...	1 Unlimited time	2	3	4	5	6	7 Very much on borrowed time
11.	Dying is the best solution for me...	1 No solution	2	3	4	5	6	7 Best solution
12.	I feel in good spirits...	1 Very poor Spirits	2	3	4	5	6	7 Excellent spirits
13.	The possibility of sudden death worries me...	1 Not at all	2	3	4	5	6	7 Very worried

14.	There is only misery in the future for me...	1 2 3 4 5 6 7 No misery ⟶ Only misery
15.	My mind is as fast and alert as always...	1 2 3 4 5 6 7 Slow and inattentive ⟶ Very fast and alert
16.	I get hardly anything done...	1 2 3 4 5 6 7 Everything done ⟶ Nothing done
17.	My problems are not yet over...	1 2 3 4 5 6 7 All problems over ⟶ Still major problems
18.	Things which I regret about my life are bothering me...	1 2 3 4 5 6 7 Absolutely no regrets ⟶ Great regrets
19.	I gain just as much pleasure from my leisure activities as I used to...	1 2 3 4 5 6 7 No pleasure at all ⟶ Very great pleasure
20.	My memory is as good as it always was...	1 2 3 4 5 6 7 Very poor memory ⟶ Excellent memory
21.	I become tearful more easily than before...	1 2 3 4 5 6 7 Not at all tearful ⟶ Very easily tearful
22.	I seem to get more easily irritated by others than before...	1 2 3 4 5 6 7 Never irritated ⟶ Very easily irritated
23.	I feel independent and in control of my life...	1 2 3 4 5 6 7 No independence ⟶ Completely independent
24.	I lose my temper more easily nowadays...	1 2 3 4 5 6 7 Never lose temper ⟶ Lose it very easily
25.	I feel frustrated...	1 2 3 4 5 6 7 Not at all frustrated ⟶ Extremely frustrated
26.	I am concerned about my capacity for sexual activity...	1 2 3 4 5 6 7 No concern at all ⟶ Grave concern

Ferrans and Powers
QUALITY OF LIFE INDEX©
CARDIAC VERSION – IV

PART 1. For each of the following, please choose the answer that best describes how **_satisfied_** you have been with that area of your life <u>during the past 1 month</u>. Please mark your answer by circling the number. There are no right or wrong answers.

HOW SATISFIED ARE YOU WITH:	Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
1. Your health?	1	2	3	4	5	6
2. Your health care?	1	2	3	4	5	6
3. The amount of chest pain (angina) that you have?	1	2	3	4	5	6
4. Your ability to breathe without shortness of breath?	1	2	3	4	5	6
5. The amount of energy you have for everyday activities?	1	2	3	4	5	6
6. Your ability to take care of yourself without help?	1	2	3	4	5	6
7. The amount of control you have over your life?	1	2	3	4	5	6
8. Your chances of living as long as you would like?	1	2	3	4	5	6
9. Your family's health?	1	2	3	4	5	6
10. Your children?	1	2	3	4	5	6
11. Your family's happiness?	1	2	3	4	5	6
12. Your sex life?	1	2	3	4	5	6
13. Your spouse, lover, or partner?	1	2	3	4	5	6
14. Your friends?	1	2	3	4	5	6
15. The emotional support you get from your family?	1	2	3	4	5	6
16. The emotional support you get from people other than your family?	1	2	3	4	5	6

(Please Go To Next Page)

HOW SATISFIED ARE YOU WITH:

		Very Dissatisfied	Moderately Dissatisfied	Slightly Dissatisfied	Slightly Satisfied	Moderately Satisfied	Very Satisfied
17.	Your ability to take care of family responsibilities?	1	2	3	4	5	6
18.	How useful you are to others?	1	2	3	4	5	6
19.	The amount of worries in your life?	1	2	3	4	5	6
20.	Your neighborhood?	1	2	3	4	5	6
21.	Your home, apartment, or place where you live?	1	2	3	4	5	6
22.	Your job (if employed)?	1	2	3	4	5	6
23.	Not having a job (if unemployed, retired, or disabled)?	1	2	3	4	5	6
24.	Your education?	1	2	3	4	5	6
25.	How well you can take care of your financial needs?	1	2	3	4	5	6
26.	The things you do for fun?	1	2	3	4	5	6
27.	Your chances for a happy future?	1	2	3	4	5	6
28.	Your peace of mind?	1	2	3	4	5	6
29.	Your faith in God?	1	2	3	4	5	6
30.	Your achievement of personal goals?	1	2	3	4	5	6
31.	Your happiness in general?	1	2	3	4	5	6
32.	Your life in general?	1	2	3	4	5	6
33.	Your personal appearance?	1	2	3	4	5	6
34.	Yourself in general?	1	2	3	4	5	6
35.	The changes in your life that you have had to make because of your heart problem (for example, changes in diet, physical activity, and/or smoking?)	1	2	3	4	5	6

(Please Go To Next Page)

PART 2. For each of the following, please choose the answer that best describes how _**important**_ that area of your life has been to you during the past 1 month. Please mark your answer by circling the number. There are no right or wrong answers.

HOW IMPORTANT TO YOU IS:	Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
1. Your health?	1	2	3	4	5	6
2. Your health care?	1	2	3	4	5	6
3. Having no chest pain (angina)?	1	2	3	4	5	6
4. Having no shortness of breath?	1	2	3	4	5	6
5. Having enough energy for everyday activities?	1	2	3	4	5	6
6. Taking care of yourself without help?	1	2	3	4	5	6
7. Having control over your life?	1	2	3	4	5	6
8. Living as long as you would like?	1	2	3	4	5	6
9. Your family's health?	1	2	3	4	5	6
10. Your children?	1	2	3	4	5	6
11. Your family's happiness?	1	2	3	4	5	6
12. Your sex life?	1	2	3	4	5	6
13. Your spouse, lover, or partner?	1	2	3	4	5	6
14. Your friends?	1	2	3	4	5	6
15. The emotional support you get from your family?	1	2	3	4	5	6
16. The emotional support you get from people other than your family?	1	2	3	4	5	6
17. Taking care of family responsibilities?	1	2	3	4	5	6

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HOW IMPORTANT TO YOU IS:

		Very Unimportant	Moderately Unimportant	Slightly Unimportant	Slightly Important	Moderately Important	Very Important
18.	Being useful to others?	1	2	3	4	5	6
19.	Having no worries?	1	2	3	4	5	6
20.	Your neighborhood?	1	2	3	4	5	6
21.	Your home, apartment, or place where you live?	1	2	3	4	5	6
22.	Your job (if employed)?	1	2	3	4	5	6
23.	Having a job (if unemployed, retired, or disabled)?	1	2	3	4	5	6
24.	Your education?	1	2	3	4	5	6
25.	Being able to take care of your financial needs?	1	2	3	4	5	6
26.	Doing things for fun?	1	2	3	4	5	6
27.	Having a happy future?	1	2	3	4	5	6
28.	Peace of mind?	1	2	3	4	5	6
29.	Your faith in God?	1	2	3	4	5	6
30.	Achieving your personal goals?	1	2	3	4	5	6
31.	Your happiness in general?	1	2	3	4	5	6
32.	Being satisfied with life?	1	2	3	4	5	6
33.	Your personal appearance?	1	2	3	4	5	6
34.	Are you to yourself?	1	2	3	4	5	6
35.	The changes in your life that you have had to make because of your heart problem (for example, changes in diet, physical activity, and/or smoking?)	1	2	3	4	5	6

Vita

Andrea Meryl Shamaskin was born on October 2, 1987, in Rochester, NY, and is an American citizen. She graduated from Brighton High School, Rochester, NY in 2005. She received her Bachelor of Science in Human Development from Cornell University, Ithaca, NY in 2009 and subsequently entered into a PhD graduate program in clinical psychology at Virginia Commonwealth University.