

LIBERTY UNIVERSITY SCHOOL OF DIVINITY

Identifying Risk Factors for and Responding to Religious/Spiritual Distress
in Transplant Patient Populations

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Thesis Defense

by

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I would like to thank my two liver donors for choosing to use their death to give the gift of life to others. I pray that I honor your lives and memories through my own life, while not forgetting that my eternal life is owed to Jesus Christ, my Lord and Savior. I would also like to thank my children for giving me a reason to fight for my life through the darkest moments of the transplant process. Finally, to my husband, Justin: thank you for supporting my goals and dreams, and for showing me what it means to love like Christ does!

Abstract

Due to the advancement of organ transplant technology, more people are able to receive a second chance at life through organ donation. In 2019, the United States conducted close to 40,000 transplants and this represents close to 40,000 people experiencing various states of healthcare crisis. Chaplains have the opportunity, and responsibility, to care for the religious/spiritual well-being of these transplant patients and their caregivers as they navigate the unique processes and challenges that transplantation entails. It is the argument of this thesis that risk factors for spiritual distress in transplant populations need to be identified as early as possible, in order to minimize potential long-term impacts. This thesis also advocates for a Biblical response to common post-transplant risk factors—especially the impact of feelings of guilt and indebtedness towards the donor. While these reactions are common amongst transplant patients, research shows they are not reported consistently, and this has concerning implications for addressing a patient’s religious/spiritual well-being.

Once someone receives an organ transplant, they are a transplant patient for the rest of their lives. It is critical to the overall health, functioning, and well-being of the patient that they are given the proper education, training, coping tools, and support to thrive with their new organ. Religious/spiritual care is an important component of transplant care that is often overshadowed by the intensive medical aspects of recovery and long-term transplant care. This thesis hopes to shed light on the unique challenges faced by transplant populations that are not widely addressed, because it is the position of this thesis that religious/spiritual distress symptoms kept in the dark and untreated are a hindrance to full recovery and healing after a life-saving transplant. Post-transplant care must focus on thriving after transplant, not merely physically surviving.

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Introduction

Statement of the Problem

Transplant recipients face unique challenges and coping processes that necessitate specialized understanding of spiritual needs and ministering approaches for healthcare chaplains. Two of the potential risks of transplantation are the burden of survivor's guilt and a feeling of indebtedness, and these responses can become obstacles to God's grace in the transplant recipient's life. Current transplant preparation does not adequately prepare transplant candidates for this possibility and how to respond to these feelings. These challenging and often unexpected reactions require uniquely sensitive spiritual care in order to reduce acute spiritual distress and safeguard against long-term negative spiritual consequences.

Statement of Purpose

The purpose of this study is to identify the risk factors for spiritual distress that commonly occur in transplant patient populations, in order to aide chaplains in providing specialized spiritual care to reduce the chance of these risk factors becoming obstacles to grace, while also encouraging positive spiritual coping after transplantation. This thesis also purposes to explore how feelings of guilt and indebtedness can become obstacles to experiencing God's grace in a transplant patient's life, in hope that this awareness will aide chaplains in assessing risk and providing spiritual care to transplant patients.

Statement of Importance of the Problem

According to 2019 statistics from the United Network for Organ Sharing (UNOS), close to 40,000 transplants were conducted across the nation, but as of April 2020 there were 112,655

people waiting for a lifesaving transplant across the nation.¹ With each awaiting and performed transplant, there is the potential for significant stress, employment of various coping strategies, and the development of spiritual distress. Additionally, once someone is a transplant patient, they are a transplant patient for the rest of their lives—transplant stressors and risks do not end with the successful transplant operation and the patient must learn how to cope with life-long needs, stressors, and effects of living with a donated organ. As one patient reported, “my scar is a reminder that it *did* happen and that something else unexpected could always be waiting.”² Risk factors, such as guilt and feelings of indebtedness can become obstacles to God’s grace, and it is the responsibility of chaplains working with transplant populations to take heed of this sobering reality. As agents of grace, chaplains must be able to identify risk factors that are unique to transplant patients and have spiritual resources ready to meet these spiritual roadblocks head on. Chaplains should be prepared to help transplant patients identify how they are feeling and help them work through these feelings in a positive and spiritually nurturing way.

Statement of Position on the Problem

It is the position of this thesis that no transplant patient should go through transplantation evaluation, wait listing, surgery, and recovery without considerable spiritual assessment to screen for common risk factors for religious/spiritual (R/S) distress. Guilt and indebtedness towards donor are not healthy coping mechanisms, and this thesis views them as obstacles to grace. Effective spiritual assessment of transplant patients may take many forms—from formal screening tools (such as the Rush protocol, N-RCOPE, Transplant Effects Questionnaire (TxEQ),

¹ "Transplant Trends," United Network for Organ Sharing, last modified April 1, 2020, accessed April 28, 2020, <https://unos.org/data/transplant-trends/>.

² Jessica Zampieri, *Surrender: What My Liver Transplant Taught Me about Control and Self- Acceptance*, 2017, kindle edition, 91.

and so on), to personal interviews, to referrals from healthcare providers. Regardless of the method used, this thesis advocates for early, consistent, and intentional screening for R/S distress and interventional strategies to remove obstacles to grace and promote positive R/S coping.

Limitations/Delimitations

This thesis assumes that the reader is at least generally acquainted with the overall process of organ transplantation, and so does not go into great detail as to the actual transplantation process a patient undergoes. This thesis also assumes that no transplant patient escapes the transplant process unscathed, and thus careful attention must be given to the coping of transplant recipients throughout the transplant process. A final limitation of this study is the suspicion that response to assessments may have been influenced by social expectations, and thus the level of R/S distress and negative coping may actually be much higher than reported in these findings.³ Research has suggested that patients are less likely to report feelings and responses they feel might make them appear ungrateful to the donor, as they feel it is viewed in a negative light by societal norms.⁴ The delimitation of this thesis is the personal connection that the researcher has to this project, as the researcher is a two-time liver transplant recipient and hopes to shine light on an area of care that was lacking throughout both transplant processes. A second delimitation of this thesis is the need to select just a few of the most commonly coping and spiritual assessment tools available to the researcher, as the scope of this thesis does not allow a thorough examination of every assessment tool currently available to assess R/S distress and coping strategies of transplant recipients.

³ Lutz Goetzmann *et al*, "Psychological Response and Quality of Life after Transplantation: A Comparison between Heart, Lung, Liver and Kidney Recipients," *Swiss Medical Weekly* 138, no. 33-34 (2008): 481, accessed April 10, 2020, <https://doi.org/2008/33/smw-12160>.

⁴ *Ibid*.

Method

Research Methods

This thesis is a descriptive study of the current methods of screening for R/S distress risk factors in the transplant population, as well as the most common stressors that can lead to R/S distress throughout the transplant process. Subsequently, this thesis analyzed the current research and proposes steps forward for chaplains to consider removing obstacles to grace within the transplant population. The research pertaining to this thesis is varied and this thesis will attempt to synthesize the available research into a cohesive application for future spiritual care for transplant patients.

Tests or Questionnaires

This thesis did not administer tests or questionnaires to transplant patients, but existing results of previously administered tests and questionnaires were included in this thesis for analysis and consideration towards the aims of this project. The most used spiritual assessment tools considered in this thesis were:

- 1) Negative Religious Coping Scale (N-RCOPE), which examines the negative effects perceived by the patient in R/S coping;⁵
- 2) Rush Protocol examines how important and meaningful R/S is to a patient;⁶

⁵ Frans J. Cronjé *et al*, "Effect Of a Faith-Based Education Program on Self-Assessed Physical, Mental and Spiritual (Religious) Health Parameters," *Journal of Religion and Health* 56, no.1 (2017): 94, accessed April 10, 2020, <https://doi.org/10.1007/s10943-015-0129-z>; George Fitchett, Patricia Murphy, and Stephen D. W. King, "Examining the Validity of the Rush Protocol to Screen for Religious/Spiritual Struggle," *Journal of Health Care Chaplaincy* 23, no. 3 (2017): 108, accessed April 10, 2020, <https://doi.org/10.1080/08854726.2017.1294861>; Stephen D.W. King *et al*, "Determining Best Methods to Screen for religious/spiritual Distress," *Supportive Care in Cancer* 25, no. 2 (2017): 472, accessed April 2, 2020, <https://doi-org.ezproxy.liberty.edu/10.1007/s00520-016-3425-6>.

⁶ King *et al*, "Determining Best Methods," 472; Fitchett, Murphy, and King, "Examining the Validity of the Rush Protocol," 99.

- 3) COPE Inventory and its variations (Brief RCOPE) examines a patient's nonreligious and religious coping strategies;⁷

This thesis also draws on the data collection and analysis of several common coping and stress inventories:

- 1) Transplant Effects Questionnaire (TxEQ) looks at the psychological effects and quality of life of transplant patients;⁸
- 2) Hospital Anxiety and Depression Scale (HADS) examines the levels of anxiety and depression present within patients, as well as assesses the risk factors for a patient developing anxiety and depression;⁹
- 3) Post-Traumatic Growth Inventory (PTGI) is used to determine how much growth is perceived by patients after a traumatic event, such as transplantation;¹⁰
- 4) Impact of Event Scale-Revised (IES-R) examines the way that individuals perceive trauma and assesses factors related to post-traumatic stress, such as hyper-arousal and avoidance.¹¹

There are, of course, many more assessment tools and this thesis may touch briefly on additional assessments throughout the course of the thesis, but the above tests and questionnaires are viewed as having the most influence on the purposes of this research.

Data Collection

The data collection for this thesis derived mainly from online library databases, and especially from the Jerry Falwell Library's online database. Additional online scholarly

⁷Eileen Burker *et al*, "Religious and Non-Religious Coping in Lung Transplant Candidates: Does Adding God to the Picture Tell Us More?" *Journal of Behavioral Medicine* 28, no. 6 (Dec 2005): 523, accessed April 2, 2020, <http://ezproxy.liberty.edu/login?url=https://search-proquest-com.ezproxy.liberty.edu/docview/231715114?accountid=12085>; A. Gurkan, S.Ç.r Pakyuz and T. Demir, "Stress Coping Strategies in Hemodialysis and Kidney Transplant Patients," *Transplantation Proceedings* 47, no. 2 (June 2015): 1393, accessed March 22, 2020, <https://doi-org.ezproxy.liberty.edu/10.1016/j.transproceed.2015.05.022>.

⁸ Goetzmann *et al*, "Psychological Response and Quality of Life after Transplantation," 477.

⁹ Gurkan, Pakyuz and Demir, "Stress Coping Strategies," 1393-1394.

¹⁰ Mijin Jeon *et al*, "Post-traumatic Growth in Survivors of Allogeneic Hematopoietic Stem Cell Transplantation," *Psycho-oncology* 24, no. 8 (2015): 872, accessed April 2, 2020, <https://doi-org.ezproxy.liberty.edu/10.1002/pon.3724>.

¹¹ *Ibid*.

databases were also used, such as Google Scholar, the directory of open-access journals, and Project Gutenberg for searching book sources. This project also utilized books purchased online and found in library databases. Research from medical journals, psychology journals, chaplaincy and religious study journals, and Scriptures found in the Holy Bible were also utilized.¹²

Data Analysis

The research for this thesis was evaluated and synthesized utilizing multiple methods, to include composing a detailed literature review matrix to better compare, contrast, and correlate data utilized. The data from various fields of research, including medical, psychology, social work, chaplaincy, and theology was compared, analyzed, and synthesized with first-person accounts from transplant recipients in order to gain a more complete picture of how transplantation affects a person's R/S coping and how best to assess their needs and minister to these needs.

Chapter One: Common Non-Religious Transplant-Related Stressors

While it is generally accepted that transplantation is a major source of stress in the transplant patient's life,¹³ there is not always a clear understanding of the widespread and all-encompassing nature of stress that the process of waiting for, receiving, and living with a transplant can cause in a recipient's life. Without intentional support present in the patient's transplant journey, the life-changing nature of transplantation has the potential to have lasting negative consequences across the full spectrum of the patient's life experiences. As such, it is

¹² Unless otherwise noted, all biblical passages referenced employ the *English Standard Version* (Wheaton, IL: Crossway, 2008).

¹³ Renato Pisanti *et al*, "Appraisal of transplant-related Stressors, Coping Strategies, and Psychosocial Adjustment Following Kidney Transplantation," *Stress and Health* 33, no. 4 (2017): 438, accessed March 22, 2020, <https://doi-org.ezproxy.liberty.edu/10.1002/smi.2727>.

important for chaplains ministering to this population to be aware of the common areas of transplant-related stress in order to best help transplant patients cope through the process. For many transplant patients, especially leading up to and for the immediate future following the transplant, transplant related stress management is an all-encompassing, full-time job.¹⁴

Physical Stressors

The transplant process presents the patient with many physical stressors, many of which have likely not been experienced to such a significant degree prior to the illness or injury that precluded the need for transplantation. Pre-transplant stressors are as widely different as the patient experiences that lead to transplantation, yet some physical stressors are common across the board. These physical stressors begin long before the actual transplant takes place and patients must be prepared for the physical toll of the evaluation process—numerous and ongoing tests and procedures take a toll on the patient’s body.¹⁵ Countless needle sticks for blood draws, IVs, and injections are common throughout the waiting process as the medical team attempts to help the patient’s body remain as strong as possible for transplantation while also managing the primary illness or injury.

The medical regimen of transplantation, which begins well before the actual transplant operation takes place, can be a burden to the patient’s life and greatly impacts every other aspect of the patient’s life.¹⁶ Symptoms related to transplant-related illness and physical decline of

¹⁴ Robert W. Shuford, "The Spiritual Journey of an Organ Transplant Patient," *Journal of Pastoral Care & Counseling* 57, no. 2 (2003): 195, accessed April 2, 2020, <https://doi-org.ezproxy.liberty.edu/10.1177%2F154230500305700209>.

¹⁵ M. Angeles Perez-San-Gregorio *et al*, "Coping Strategies in Liver Transplant Recipients and Caregivers According to Patient Posttraumatic Growth," *Frontiers in Psychology* (January 2017): 1, accessed April 2, 2020, https://link.gale.com/apps/doc/A478260662/HRCA?u=vic_liberty&sid=HRCA&xid=2db11af5.

¹⁶ Jiayun Xu *et al*, "Daily Burdens of Recipients and Family Caregivers After Lung Transplant," *Progress in Transplantation* 22, no. 1 (March 2012): 41, accessed May 19, 2020, <http://dx.doi.org/10.7182/pit2012815>.

health can cause complications across all aspects of coping and daily functioning, including all other areas of stressors—financial, vocational, relational, emotional, and spiritual. Transplant care teams must encourage patients to communicate their physical symptoms openly and honestly so that all efforts may be made to optimize physical functioning and promote symptom management as far as is feasible throughout the arduous transplant process. Symptom management can be a confusing and complicated process, often attempting to maintain a balance between desired outcomes versus side effects brought about symptom management. These efforts all too often do not stop the decline in physical health and functioning the longer the patient remains on the transplant waiting list, and declining health contributes significantly to the stress experienced throughout the transplant process.¹⁷

The transplant process not only takes a toll on the experience of physical symptoms, such as pain and decreased physical functioning of the body, transplantation also alters the physical appearance of the patient's body. Weight gain from post-transplant steroids can cause significant stress in patients, as can the appearance of scars after the transplant.¹⁸ These body image issues can be difficult for patients to cope with and caregivers should note the increased possibility for psychological distress when there is discontentment related to body image post-transplant.¹⁹ While the majority of patients perceive the physical changes as manageable, the care giving team should evaluate for potential distress and address concerns over body image issues, as well as the

¹⁷ Eileen Burker *et al*, "Religious and Non-Religious Coping in Lung Transplant Candidates: Does Adding God to the Picture Tell Us More?" *Journal of Behavioral Medicine* 28, no. 6 (Dec 2005): 513, accessed April 2, 2020, <http://ezproxy.liberty.edu/login?url=https://search-proquest-com.ezproxy.liberty.edu/docview/231715114?accountid=12085>.

¹⁸ Kathy L. Coffman and Maria Z. Siemionow, "Face Transplantation: Psychological Outcomes at Three-Year Follow-Up," *Psychosomatics* 45, no. 4 (2013): 376, accessed May 5, 2020, <https://doi.org/10.1016/j.psych.2012.10.009>.

¹⁹ Yaron Yagil *et al*, "Body-Image, Quality of Life and Psychological Distress: A Comparison Between Kidney Transplant Patients and a Matching Healthy Sample," *Psychology, Health, & Medicine* 23, no. 4 (2018): 430-431, accessed May 19, 2020, <https://doi.org/10.1080/13548506.2017.1400668>.

presence of any physical stressors in order to ensure that all efforts are made to promote positive coping with this impactful area of transplant related stress.

Emotional/Psychological

Emotional and psychological stress is arguably the most significant area of non-religious transplant-related stress for patients, as it impacts the patient's perceived quality of life, which affects how the patient copes with the transplant and how likely they are to adhere to the transplant medical regimen.²⁰ Poor emotional and psychological coping, when it contributes to non-adherence to post-transplant care, leads to increased medical costs, increased likelihood of graft failure, and higher chance of post-transplant morbidity.²¹ The consequences of elevated emotional and psychological stress have life-threatening potential in transplant patients, thus these common stressors must be understood and addressed at the earliest possible signs throughout the course of the transplant process.

One of the most common emotional stressors in transplant populations is fear—first of not receiving a transplant in time²² and then of that transplanted organ rejecting.²³ The potential for organ failure is a concern that never goes away for transplant patients—organs can fail even after decades of successful integration and despite all efforts made to follow medical protocol

²⁰ Pisanti *et al*, "Appraisal of transplant-related Stressors," 437.

²¹ Yedida Shemesh *et al*, "Feelings of Indebtedness and Guilt toward Donor and Immunosuppressive Medication Adherence among Heart Transplant (HTx) Patients, as Assessed in a Cross-sectional Study with the Basel Assessment of Adherence to Immunosuppressive Medications Scale (BAASIS)," *Clinical Transplantation* 31, no. 10 (2017):1, accessed April 3, 2020, <https://doi.org/10.1111/ctr.13053>.

²² Burker *et al*, "Religious and Non-Religious Coping," 513.

²³ Konstadina Griva *et al*, "Quality of Life and Emotional Responses in Cadaver and Living Related Renal Transplant Recipients," *Nephrology, Dialysis, Transplantation: Official Publication of the European Dialysis and Transplant Association - European Renal Association* 17, no. 12 (2002): 2207, accessed April 2, 2020, <https://doi.org/10.1093/ndt/17.12.2204>; Perez-San-Gregorio *et al*, "Coping Strategies in Liver Transplant Recipients," 1; Renato Pisanti *et al*, "The Role of Transplant-Related Stressors and Social Support in the Development of Anxiety Among Renal Transplant Recipients: The Direct and Buffering Effects," *Psychology, Health & Medicine* 16, no. 6 (2014): 650, accessed May 19, 2020, <http://dx.doi.org/10.1080/13548506.2014.882514>.

and this chronic threat can take an emotional toll on transplant patients.²⁴ Understandably, this fear and chronic stress can also lead to an increased risk of Post-Traumatic Stress Disorder (PTSD) for the patient and this risk must be addressed at the earliest signs of distress.²⁵ When PTSD is suspected, it is critical that transplant patients are referred to qualified, professional mental health professionals and that necessary supports are put into place to help the patient understand and cope with the aspects of their experiences that contributed to the development of PTSD.

Perhaps more common than PTSD among transplant patients, the development of anxiety and/or depression is common within transplant patient populations. Studies of liver transplant recipients have found that 71% of liver recipients experience some degree of depression, with 45% experiencing anxiety, and 20% experiencing behavior disorders after the transplant.²⁶ Research conducted with kidney recipients showed evidence of depression in 25% of recipients and depression in half of the recipients evaluated.²⁷ Alarming, a correlation has been found between these mental health symptoms and the increased likelihood for poorer transplant outcomes, as anxiety has been found to be associated with mental disengagement, while depression has been “strongly associated with behavioral disengagement.”²⁸ These correlations have the potential for long-term consequences for transplant success, as disengagement can lead

²⁴ Ana Hategan, Charles Nelson, and Sarah Jarman, “Heart Transplant, Social Support, and Psychiatric Sequelae: A 10-Year Follow-Up Clinical Case Review,” *Psychosomatics* 49, no. 1 (2008): 41, accessed May 19, 2020, <http://ezproxy.liberty.edu/login?url=https://search-proquest-com.ezproxy.liberty.edu/docview/220332803?accountid=12085>; Paul Gill, “Stressors and Coping Mechanisms in Live-Related Renal Transplantation,” *Journal of Clinical Nursing* 21 (2012): 1626, accessed May 19, 2020, <http://dx.doi.org/10.1111/j.1365-2702.2012.04085.x>.

²⁵ Hategan, Nelson, and Jarman, “Heart Transplant, Social Support, and Psychiatric Sequelae,” 41.

²⁶ H. Pelgur, N. Atak, and K. Kose, “Anxiety and Depression Levels of Patients Undergoing Liver Transplantation and Their Need for Training,” *Transplantation Proceedings* 4, no.5 (2009): 1743, accessed April 10, 2020, <https://doi.org/10.1016/j.transproceed.2008.11.012>.

²⁷ Pisanti *et al*, “Appraisal of transplant-related Stressors,” 437.

²⁸ Burker *et al*, “Religious and Non-Religious Coping,” 514.

to non-adherence to medical regimen and ignoring symptoms that need medically addressed. With the limited availability of donated organs, it is vital that transplant recipients do all they can to maintain the organ, and as such anxiety and depression must be evaluated and treated at the earliest possible sign of their presence. The caregiving team must maintain open communication with the patient so that emotional and psychological stressors do not go unnoticed.

Financial and Vocational

As of January 2020, the Milliman Research Report estimates the costs of organ transplant to range at the low end of roughly \$32,500 for a cornea transplant upwards to more than \$1.6 million for a heart transplant, and these costs only include up to 180 days post-transplant.²⁹ Transplant patients incur great financial burden for the entire life of their transplant, as the costs do not go away after the initial in-hospital recovery. For many transplant patients, “economic survivorship stressors” of transplantation include the actual financial costs of transplant, employment stressors, and insurance stressors that must all be navigated as a result of needing an organ transplant.³⁰ Not only do patients have to contend with the actual costs of the transplant-related medical procedures leading up to, during, and after the transplant, but they must also factor in financial costs of transportation fees, extensive medications, and lodging for patients that do not live close to their transplant center.³¹ When patients perceive their ability to meet these financial demands as stressful or inadequate there is a decreased health-related quality of life experienced for the patient, which can magnify both physical and psychological transplant

²⁹ T. Scott Bentley and Nick J. Ortner, “2020 U.S. Organ and Tissue Transplants: Cost Estimates, Discussion, and Emerging Issues,” *Milliman Research Report* (Jan 2020): 5, accessed June 10, 2020, <https://milliman-cdn.azureedge.net/-/media/milliman/pdfs/articles/2020-us-organ-tissue-transplants.ashx>.

³⁰ Jada G. Hamilton *et al*, “Economic Survivorship Stress is Associated with Poor Health-Related Quality of Life Among Distressed Survivors of Hematopoietic Stem Cell Transplantation,” *Psycho-Oncology* 22 (2013): 911, accessed May 19, 2020, <https://dx.doi.org/10.1002/pon.3091>.

³¹ *Ibid.*, 912.

stressors already present.³² Additionally, the economic survivorship stressors contribute to the overall burden of transplant related functioning as well, again contributing to increased risk to the longevity of the transplanted organ.³³

The financial stressors are directly influenced by vocational stressors. Due to the prolonged timeline of waiting for, receiving, and recovering from a transplant, many transplant patients either significantly decreased the amount they are working or quit working either temporarily or permanently.³⁴ The loss of employment contributes to the financial burden of paying for transplant-related costs, and many patients find they are unable to return to their previous level of employment because they can no longer perform their work-related tasks even after recovery from transplant.³⁵ Employers may also be unsupportive of the demands that a transplant places on a transplant employee's schedule, energy levels, and productivity due to managing symptoms, side effects, and stress related to the transplant,³⁶ making employment another source of stress for the transplant patient.

Relational

Social support is a foundational need for someone needing and undergoing a transplant, with the presence of positive social support even having positive effects on coping with chronic stress as experienced in the transplant process.³⁷ When a transplant patient has a higher level of perceived social support there is evidence of lower rates of psychological distress,³⁸ which in

³² Ibid., 911-912.

³³ Ibid., 917.

³⁴ Shuford, "The Spiritual Journey of an Organ Transplant Patient," 192.

³⁵ Hamilton *et al*, "Economic Survivorship Stress," 912.

³⁶ Ibid.

³⁷ Hategan, Nelson, and Jarmain, "Heart Transplant, Social Support, and Psychiatric Sequelae," 40.

³⁸ Pisanti *et al*, "The Role of Transplant-Related Stressors," 651.

turn reduces risks of non-adherence and other negative coping mechanisms post-transplant.³⁹ In light of this important relationship between coping and relational support, a supportive caregiving relationship must be identified and nurtured throughout the transplant process. In the event that a transplant patient is married, this caregiving role is often filled by a spouse, and this can bring many challenges, as well as opportunities for growth, to the marital relationship. Specifically, the financial, emotional, and physical burdens of the transplant process can introduce strain into the patient's relationships and proactive measures are helpful to prepare for the patient and their caregivers for these potential stressors.⁴⁰ Whether married or not, a supportive and committed care giving relationship is vital to coping through the transplant process, and stress on this relationship can be reduced through appropriate and proactive education and preparation of the transplant and its related stressors prior to the time of transplant.

Summary

The process of transplantation affects every aspect of a recipient's life—physical, emotional/psychological, financial, relational, and vocational.⁴¹ The transplant patient will face challenges throughout the transplant process⁴²—from evaluation, to waitlist, to transplant surgery, to recovery—that often leaves them feeling isolated and set apart from non-transplant patients. Learning to accept physical limitations and changes to one's body greatly effects a transplant patient's daily functioning and can lead to a negative body image from scarring and

³⁹ Hategan, Nelson, and Jarmain, "Heart Transplant, Social Support, and Psychiatric Sequelae," 39.

⁴⁰ *Ibid.*, 40.

⁴¹ Renato Pisanti *et al*, "Appraisal of transplant-related Stressors, Coping Strategies, and Psychosocial Adjustment Following Kidney Transplantation," *Stress and Health* 33, no. 4 (2017): 438, accessed March 22, 2020, <https://doi-org.ezproxy.liberty.edu/10.1002/smi.2727>.

⁴² Coffman and Siemionow, "Face Transplantation," 372–78; Kathleen Grady *et al*, "Factors Associated with Stress and Coping at 5 and 10 Years after Heart Transplantation," *Journal of Heart and Lung Transplantation* 32, no. 4 (April 2013): 437-440, accessed April 2, 2020, <https://dx.doi.org/10.1016/j.healun.2012.12.012>.

medication side effects.⁴³ Emotional stressors, such as anxiety and depression, are also an increased possibility for transplant patients, and the caregiving team must be diligent in assessing for these stressors.⁴⁴

Additionally, transplant patients often struggle with strained relationships due to the intense nature of transplantation and the long term effects it has on the patient and loved ones—especially when the patient is married, as roles and dynamics must shift and change to accommodate the transplantation process.⁴⁵ Relatedly, financial stressors caused by the high cost of transplantation, medication, and additional expenses are often burdensome to both patient and their caregiver,⁴⁶ which only adds to potential relational strain as well. Financial stressors are often exacerbated by the vocational stressors that accompany transplantation, as transplant patients are often out of work for extended periods of time, if not permanently, first due to the illness that leads to transplantation, and then due to the lengthy recovery process after transplantation and sometimes decreased capacity to return to the work force.⁴⁷

Chapter Two: Risk Factors for Spiritual Distress in Transplant Patients

While non-religious stressors factor into a chaplain's assessment and care plan for transplant patient, it is spiritual distress that is the central focus, and which must be most carefully assessed and then addressed by the spiritual care team. In order to provide specialized spiritual care to transplant patients, chaplains must understand the unique challenges that

⁴³ Griva *et al*, "Quality of Life," 2207.

⁴⁴ Grady *et al*, "Factors Associated with Stress and Coping," 437; Griva *et al*, "Quality of Life," 2210.

⁴⁵ Jeon *et al*, "Post-traumatic Growth," 873-876; Shuford, "The Spiritual Journey of an Organ Transplant Patient," 192; Najmeh Valizadeh *et al*, "The Sources of Stress in Renal Transplant Patients," *Journal of Evidence-Based Care* 5, no.4 (2015): 63, accessed April 10, 2020, <https://doi.org/10.22038/ebcj.2015.6378>.

⁴⁶ Somayeh Saadatpanah *et al*, "Relationship between Coping and Spiritual Health in Renal Transplant Recipients," *Journal of Evidence-Based Care* 7, no. 4 (2018):74, accessed March 20, 2020, <https://dx.doi.org/10.22038/ebcj.2017.26137.1603>.

⁴⁷ Grady *et al*, "Factors Associated with Stress and Coping," 439.

transplant patients often face as obstacles to spiritual well-being: feelings of guilt, indebtedness, and poor coping of transplant-related stressors. In order to promote R/S coping and growth, it is essential that transplant patients recognize and address these challenges as they are obstacles to fully experiencing and living in God's grace and the freedom of Christ. Chaplains will likely find that discussing feelings of transplant-related guilt and indebtedness are difficult for many transplant patients,⁴⁸ and that they may even be unaware of how to even identify these feelings within themselves.

Guilt

Feelings of guilt towards the organ donor are not always easily identified, yet studies show they are often present after the transplant and can have devastating consequences when unacknowledged and not dealt with in positive manner.⁴⁹ Specifically, guilt towards the donor and donor family is directly associated with increased worry and an increased feeling of responsibility for the organ, as well as associated with lower medication and treatment adherence.⁵⁰ If these feelings are not addressed at their root, the chance of organ failure increases due to lower adherence to medication therapies, such as the immunosuppressive (IS) therapy required to prevent the body of rejecting the organ.

Initially, it would seem that guilt would be higher in the case of cadaveric donors, yet research actually shows that, when applicable, recipients of living donation experience higher rates of guilt towards their donors than do those of cadaveric donation.⁵¹ In the case of living donation, recipients tend to have some sort of relationship with their donors or donor families, and thus have

⁴⁸ Shuford, "The Spiritual Journey of an Organ Transplant Patient," 194.

⁴⁹ Griva *et al*, "Quality of Life," 2207.

⁵⁰ *Ibid*.

⁵¹ Shemesh *et al*, "Feelings of Indebtedness and Guilt," 2.

a firsthand awareness of the sacrifices made by the donor in order to give the recipient the gift of life, especially the risks to the donor's own health through the donation process.⁵² Understanding the risks, the physical side effects, and the potential long-term consequences of live donation may lead the recipient to feel as if they are to blame for the impact on the donor and these feelings of guilt can negatively impact their coping of not only the transplant itself, but their R/S coping as well.

Cadaveric donor-related guilt is somewhat more straightforward than guilt related to living donation yet can be more challenging for R/S coping efforts. When the donor is still living, such as in living kidney donation, the recipient can be reassured by the donor that the gift of life was a positive choice on the donor's part. When the organ comes from a cadaveric donor, the recipient lives with the knowledge that the transplant was only possible as the result of someone else's death, and this awareness can lead to R/S distress and feelings of guilt that cannot be alleviated by the donor. The guilt, when not recognized and appropriately dealt with, can raise severe difficulties for the recipient, as it can lead to an inability to accept the organ and this refusal can lead to organ rejection, as well as long-lasting R/S consequences when there is unsettled internal struggle that manifests in physical effects of organ rejection.⁵³

Another common area of guilt faced by transplant recipients is the guilt they may feel when they receive an organ before other patients that have been waiting longer, those who seem in greater need, and especially when they receive an organ while others die without the needed organ.⁵⁴ Compounding these feelings of guilt is the result that transplant recipients often feel guilty for feeling any of these emotions that they perceive as inappropriate—with the gift of life

⁵² Griva *et al*, "Quality of Life," 2208.

⁵³ Perez-San-Gregorio *et al*, "Coping Strategies in Liver Transplant Recipients," 7.

⁵⁴ Burker *et al*, "Religious and Non-Religious Coping," 513.

sometimes comes the unrealistic expectation that all coping will be positive and all post-transplant feelings will be positive in nature.⁵⁵

Recipients that receive organs from cadaveric donors experience this complicated web of guilt that can best be understood as transplant survivor's guilt—guilt feelings internalized as a result of feeling that they survived because their donor's life ended. While the recipient may understand, at least on some level, that their transplant is not the reason their donor died and that donation gives a positive outcome to the tragedy of death, recipients may still struggle to live with these feelings of guilt. Survivor's guilt can lead to a serious R/S struggle and even to a crisis of faith even in people with a seemingly firm faith foundation prior to transplantation. It is important that the transplant care team be alert to signs of R/S distress, such as the patient expressing feelings of guilt related to their transplant, and report any such signs to the spiritual care team for further assessment.⁵⁶

Survivor guilt necessitates special consideration and understanding for those working alongside transplant patient populations. Research shows that this type of guilt can adversely affect mental health, as well as a patient's interactions with their healthcare providers and caregivers.⁵⁷ Transplantation demands a complex cooperation between a vast multidisciplinary team, the patient, and the patient's caregiver and the potential of survivor guilt to impede this process necessitates its early identification and resolution. When left unidentified and unresolved,

⁵⁵ Janet Jones *et al*, "You Have Got a Foreign Body in There': Renal Transplantation, Unexpected Mild-to-Moderate Distress and Patients' Support Needs: A Qualitative Study," *BMJ Open* 10, no. 3 (2020): 4, accessed April 2, 2020, <https://doi.org/10.1136/bmjopen-2019-035627>.

⁵⁶ Griva *et al*, "Quality of Life," 2210.

⁵⁷ Sadie P. Hutson, Joanne M. Hall, and Frankie L. Pack, "Survivor's Guilt: Analyzing the Concept and Its Contexts," *Advances in Nursing Science* 38, no. 1 (2015): 21, accessed June 12, 2020, <https://dx.doi.org/10.1097/ANS.000000000000058>.

survivors' guilt can unconsciously lead the patient towards self-sabotage of reaching their goals, which can also inhibit the physical success of the transplant.⁵⁸

Not only can it lead to self-sabotage, but this type of guilt can also lead to many other consequences and risk factors for its development must be understood and patients assessed for these factors. Researchers have identified common antecedents that often preclude the development of survivors' guilt. Personal characteristics of strong empathy or perfectionism predispose a patient more towards guilt than someone who is lacking these characteristics.⁵⁹ An actual or perceived identification with the donor is also a risk factor for survivors' guilt (e.g., the female recipient discovers that the donor was also a mother that left children behind).⁶⁰ When the recipient has a sense strong of fairness he or she is more likely to perceive culpability for the donor's death, questioning why someone else's life ended yet spared the recipient's life while others die without a transplant at the same time.⁶¹

When any of these factors are present, the caregiving team must be alert for signs of survivors' guilt and be further aware of common traits of the experience of this guilt. Survivors' guilt is directly connected to the loss of the donor's life or the loss of other patients on the waiting list while the recipient was spared from this loss.⁶² Survivors' guilt is always adversely experienced, highly individualized and manifests in a variety of ways in each unique situation.⁶³ In other words, survivors' guilt is a process, often cyclic and unpredictable in duration and intensity—there is no universal pattern or process towards resolution. Without resolution, the

⁵⁸ Ibid., 24.

⁵⁹ Ibid., 27.

⁶⁰ Ibid.

⁶¹ Ibid.

⁶² Ibid., 24.

⁶³ Ibid., 24-25.

consequences of survivors' guilt can be severe and result in altered relationships, mental health challenges, as well as physical symptoms.⁶⁴ Symptoms such as anger, sadness, stress, anxiety, perfectionism, insomnia, ulcers, self-harm behaviors, development of Post-Traumatic Stress Disorder (PTSD), and clinical depression are all possible experiences of survivors' guilt and the presence of these symptoms should prompt the caregiving team to assess for survivors' guilt.

Resolution of survivors' guilt is possible and necessary to protect against R/S distress. In order to do this, chaplains must help patients recognize the presence of survivors' guilt, confront their responses to this guilt, and guide patients to face the emotions they are experiencing as a result of the transplant. Chaplains have a responsibility to encourage resolution of those guilty feelings. Later chapters will focus on how chaplains should approach the presence of guilt from a Biblical standpoint and address it must be. Positive coping with transplantation cannot happen if guilt remains.

Indebtedness

Transplant recipients that experience survivors' guilt often struggle with a feeling of indebtedness to the organ donor as well. This feeling of indebtedness is experienced as a sense of obligation to repay the donor for the gift of life received through the organ donation and is experienced by an overwhelmingly large number of recipients post-transplant.⁶⁵ Transplant recipients may understand that there is no way that they can repay the gift of donation, yet this knowledge doesn't eliminate the fact that many recipients still feel a sense of indebtedness

⁶⁴ Ibid., 28.

⁶⁵ Shemesh *et al*, "Feelings of Indebtedness and Guilt," 2-4.

towards their donor and donor family and this feeling is a powerful force in the experiences of a transplant recipient.

Some research shows that more than 70% of transplant recipients experience indebtedness towards their donor, the family, and even the healthcare team and their caregivers for the sacrifices that are made for the recipient's health.⁶⁶ This feeling of indebtedness is a risk factor for R/S distress when it motivates the recipient to attempt to prove they are worthy or deserving of the sacrifices made by a living donor, or the death of a cadaveric donor. The presence of a feeling of indebtedness by the recipient is an opportunity for the spiritual care team to offer assessment and develop appropriate intervention measures to encourage positive processing of these feelings so that appropriate coping and resolution can be promoted throughout the recovery and ongoing life experiences of the transplant recipient.

Poor Coping with Transplant-Related Stressors

Transplant recovery is a life-long process that does not end with post-transplant hospital discharge. Due to the complex and unpredictable nature of transplants, patients will have to contend with transplant-related stressors for the life of their transplant. As such, it is important that adequate preparation is made to promote and encourage continued coping throughout the entire transplant process and throughout recovered living. Much research exists that illustrate the need for appropriate coping mechanisms in the face of trauma, and transplantation is certainly a form of trauma for the recipient, and without understanding these coping techniques there is an increased chance of R/S distress as a result of transplantation.

⁶⁶ Lutz Goetzmann *et al*, "Psychological Response and Quality of Life after Transplantation: A Comparison between Heart, Lung, Liver and Kidney Recipients," *Swiss Medical Weekly* 138, no. 33-34 (2008): 481, accessed April 10, 2020, <https://doi.org/2008/33/smw-12160>.

While each patient will cope differently to the transplant process, as each transplant experience is unique, there is a demonstrated difference between the effectiveness of various coping styles. Passive or avoidant coping styles have proven to be less effective for promoting positive coping throughout the transplant process, instead leading to psychological distress, mental disengagement, higher rates of depression, and overall maladjustment to the transplant.⁶⁷ Additionally, emotionally oriented coping styles also lead to poor adjustment and are correlated with higher levels of guilt towards the donor.⁶⁸ Denial and avoidance do not promote post-transplant growth and coping, but interfere with the adaption required of transplant recipients and have been shown to even lead to non-adherence to medications and medical regimens necessary for transplant survival.⁶⁹ Studies done comparing the effects of transplant across the different organ groups have shown that there is a higher risk of poor coping and distress amongst kidney and liver transplant patients, and thus these two organ groups would benefit from more frequent and thorough assessment of coping processes and transplant-related stressors throughout the entire course of transplantation.⁷⁰

Most significant for chaplains and the spiritual care team is when recipients view their transplant-related illness or injury as punishment from God—this negative coping mechanism should immediately prompt the care team to provide further assessment and spiritual care.⁷¹ If the patient does view their transplant as a result of punishment from God, higher rates of depression and anxiety tend to follow, as well as the recipient being more likely to view themselves as disabled⁷²—all of which are road blocks to appropriate coping and positive

⁶⁷ Burker *et al*, "Religious and Non-Religious Coping," 524.

⁶⁸ Pisanti *et al*, "Appraisal of transplant-related Stressors," 444.

⁶⁹ *Ibid*.

⁷⁰ Goetzmann *et al*, "Psychological Response and Quality of Life after Transplantation," 482.

⁷¹ Burker *et al*, "Religious and Non-Religious Coping," 524.

⁷² *Ibid.*, 514.

management of transplant-related stressors and lead to a higher likelihood of developing R/S distress.⁷³

Summary

Chaplains working with transplant populations need to be able to recognize the impact of non-religious stressors on the patient, while also paying even closer attention to the R/S distress risks. Chaplains are agents of God's grace and hope through what are some of the most challenging experiences a person can face. Guilt, a sense of indebtedness, and poor coping are all obstacles to experiencing God's grace and must be understood, assessed, and ministered to throughout the transplant process.⁷⁴ Transplant patients can suffer guilt towards either a living donor⁷⁵ or a cadaveric donor⁷⁶ for the sacrifice made for the recipient to receive a transplant. Guilt may also surface when a patient feels they received an organ sooner than others who were waiting longer.⁷⁷ After a transplant, many recipients feel they should not be feeling negative emotions, as this makes them feel guilty for their perception of negative emotions equating to

⁷³ Ibid.

⁷⁴ Pisanti *et al*, "Appraisal of transplant-related Stressors," 437; Shuford, "The Spiritual Journey," 194.

⁷⁵ Griva *et al*, "Quality of Life," 2206-2208; Yedida Shemesh *et al*, "Feelings of Indebtedness and Guilt toward Donor and Immunosuppressive Medication Adherence among Heart Transplant (HTx) Patients, as Assessed in a Cross-sectional Study with the Basel Assessment of Adherence to Immunosuppressive Medications Scale (BAASIS)," *Clinical Transplantation* 31, no. 10 (2017): 2, accessed April 3, 2020, <https://doi.org/10.1111/ctr.13053>.

⁷⁶ H. Pelgur, N. Atak, and K. Kose, "Anxiety and Depression Levels of Patients Undergoing Liver Transplantation and Their Need for Training," *Transplantation Proceedings* 4, no.5 (2009): 1743, accessed April 10, 2020, <https://doi.org/10.1016/j.transproceed.2008.11.012>; M. Angeles Perez-San-Gregorio *et al*, "Coping Strategies in Liver Transplant Recipients and Caregivers According to Patient Posttraumatic Growth," *Frontiers in Psychology* (January 2017): 7, accessed April 2, 2020, https://link.gale.com/apps/doc/A478260662/HRCA?u=vic_liberty&sid=HRCA&xid=2db11af5; Shemesh *et al*, "Feelings of Indebtedness and Guilt," 2.

⁷⁷ Janet Jones *et al*, "'You Have Got a Foreign Body in There': Renal Transplantation, Unexpected Mild-to-Moderate Distress and Patients' Support Needs: A Qualitative Study," *BMJ Open* 10, no. 3 (2020): 4, accessed April 2, 2020, <https://doi.org/10.1136/bmjopen-2019-035627>.

ungratefulness,⁷⁸ or even guilty feelings resulting from wishing for an organ transplant that they knew would mean someone else would have to die.⁷⁹

Much like guilt, a feeling of indebtedness to the donor and donor family can severely hinder positive coping and R/S health. Recipients often struggle with feeling that they must do something to repay the donor, yet feel lost when they realize they cannot repay their donor—especially when their donor was a deceased donor.⁸⁰ It is noteworthy that in one study of post-transplant coping, 69.7% of patients studied reported they felt indebted to their donor and needed to find a way to be worthy of their sacrifice.⁸¹ Indebtedness is found to be a common reaction to transplantation that has serious implications for chaplains as they seek to encourage and promote healthy R/S growth.⁸²

Another consideration when considering R/S distress in the transplant population is the presence of poor coping with the previously discussed non-religious stressors. Research shows that several coping styles are not conducive to post-transplant growth and coping—especially the coping styles that focus on emotional and avoidant techniques.⁸³ Many of the pre-transplant stressors are expected to fade after a transplant takes place, when in fact this is rarely the case

⁷⁸ *Ibid.*, 4-5.

⁷⁹ Pelgur, Atak, and Kose, "Anxiety and Depression Levels of Patients," 1743.

⁸⁰ Jones *et al.*, "You Have Got a Foreign Body in There," 6; Shemesh *et al.*, "Feelings of Indebtedness and Guilt," 2.

⁸¹ Shemesh *et al.*, "Feelings of Indebtedness and Guilt," 2.

⁸² Goetzmann *et al.*, "Psychological Response and Quality of Life after Transplantation," 481; Yousheng Lester Lai *et al.*, "Comparing Emotional Adjustment of Living-Donor and Deceased-Donor Kidney Transplant Patients," *Transplantation Direct* 6, no. 2 (2020): 2, accessed April 10, 2020, <https://doi.org/10.1097/TXD.0000000000000956>.

⁸³ Burker *et al.*, "Religious and Non-Religious Coping," 524; Pisanti *et al.*, "Appraisal of transplant-related Stressors," 444.

and this unmet expectation can lead to R/S distress if not recognized and addressed in a positive manner.⁸⁴

Chapter Three: Screening Tools

Research consistently demonstrates a relationship between health and spiritual well-being, and as such it is important for people undergoing stressful medical processes to receive appropriate and timely R/S assessment by spiritual care professionals.⁸⁵ Chaplains use a variety of screening tools when assessing for R/S distress in hospitalized populations. This chapter gives a brief overview of several common screening tools that pertain to the transplant population. Religion and coping merge together when people with R/S convictions face, and must cope with, major life-stressors.⁸⁶ As transplantation is arguably a major life stressors, this chapter also describes several common types of tools used to evaluate coping and stress within transplant patients. Early and consistent evaluation can detect and address R/S distress and struggle in order to increase positive coping, increase quality of life, and increase functioning post-transplant so as to increase the chance of transplant success on the patient's part.

N-RCOPE

The Negative Religious Coping (N-RCOPE) scale is a 7-item screening tool that evaluates the presence “spiritual discontent, perceived spiritual punishment and harmful spiritual influences related to illness.”⁸⁷ The N-RCOPE allows chaplains to identify patients that are most at risk for R/S distress and poorer coping with transplant-related stressors by identifying negative

⁸⁴ Ragny Lindqvist, Marianne Carlsson, and Per-Olow Sjödén, “Coping Strategies of People with Kidney Transplants,” *Journal of Advanced Nursing* 45, no. 1 (Jan 2004):48, accessed April 2, 2020, <https://doi-org.ezproxy.liberty.edu/10.1046/j.1365-2648.2003.02859.x>.

⁸⁵ Saadatpanah *et al*, "Relationship between Coping and Spiritual Health," 74.

⁸⁶ Burker *et al*, "Religious and Non-Religious Coping," 514.

⁸⁷ Cronjé *et al*, “Effect Of a Faith-Based Education Program,” 94.

R/S associations.⁸⁸ Specifically, the N-RCOPE gives chaplains a picture of how a patient views God's role in the illness that led to the need for transplantation, as a reported feeling of punishment or abandonment by God (or the patient's different idea of a higher power) indicated immediate risk of R/S distress and need for spiritual intervention.⁸⁹ According to the developers of the Rush protocol, the N-RCOPE is one of the most commonly used R/S assessment tools due to its high degree of validity and reliability, as well as its simplicity to administer.⁹⁰

Rush Protocol

The Rush Protocol is another widely used R/S distress screening tool, developed to attempt to help identify patients that need spiritual care or who are potential candidates for R/S struggle.⁹¹ This protocol approaches R/S struggle from a broader and more general lens than the N-RCOPE, asking the patient to evaluate how important religion or spirituality is for the coping of their illness.⁹² Based on the patient's answer, the patient is directed to pathway one (R/S is important in coping with their illness) or pathway two (R/S is not important in their coping with their illness).⁹³ Pathway one then asks the patient about their level of satisfaction with how R/S is supporting them through their illness, with patients answering with "less than I need or none at all" indicating the possibility of R/S distress and the need for R/S care intervention.⁹⁴ On the other hand, patients that answered that R/S was unimportant are guided to pathway two and asked if R/S was ever important to them, with answers of "no" indicating no R/S struggle, but an

⁸⁸ Ibid.

⁸⁹ King *et al*, "Determining Best Methods," 472.

⁹⁰ Fitchett, Murphy, and King, "Examining the Validity of the Rush Protocol," 103.

⁹¹ Ibid., 99.

⁹² King *et al*, "Determining Best Methods," 472.

⁹³ Ibid.; Fitchett, Murphy, and King, "Examining the Validity of the Rush Protocol," 101.

⁹⁴ Ibid.

answer of “yes” indicating that there could possibly be unresolved R/S struggle present and further assessment may be appropriate.⁹⁵

COPE Inventory and Its Variations

The COPE Inventory is used as a patient self-reporting tool that assesses 14 types of coping styles, including a section on “turning to God”.⁹⁶ Much like non-religious coping styles, Burker *et al* view religious coping styles as being active, passive, emotional, or interpersonal in nature and the COPE Inventory and its variations, such as the RCOPE, assess these coping styles in order to give chaplains a better understanding of how a patient is responding to transplantation and any R/S distress.⁹⁷ These inventories can be used in specific situations, such as during transplant hospital recovery, or they can also be used to assess the patient’s dispositional religious coping style and can be helpful then at the earliest stage of the transplant evaluation to assess a patient’s potential for current or future R/S distress throughout the transplant process.⁹⁸ Unlike the more vague subscale of the COPE Inventory, the RCOPE specifically evaluates 5 key religious functions and how someone copes in each of its subscales.⁹⁹

Transplant Effects Questionnaire (TxEQ)

The TxEQ is a questionnaire intended to evaluate a transplant recipient’s emotional and behavioral response to transplant through examining 5 common factors specific to transplantation: worry about the transplant, guilt towards the donor, disclosure about transplant,

⁹⁵ Ibid.

⁹⁶ Burker *et al*, "Religious and Non-Religious Coping," 516-517.

⁹⁷ Ibid., 514.

⁹⁸ Ibid., 516.

⁹⁹ Ibid.

adherence to medical regimen, and responsibility towards caregivers and medical team.¹⁰⁰

Specifically, the TxEQ looks at the health-related behaviors of recipients post-transplant, as these and the emotional responses of the recipient seems to reflect both “the subtle and complex cognitive, emotional, and behavioral process after transplantation.”¹⁰¹ The TxEQ also gives a picture of the quality of life and psychological functioning of transplant recipients post-transplant, which are both shown to be linked to overall health and spiritual well-being.¹⁰² With this in mind, it is important for chaplains ministering to transplant recipients to consider the TxEQ as a valuable tool for assessment and screening for potential R/S distress, as R/S distress can follow poor emotional, behavioral, and psychological coping with transplantation.

Important to note about the TxEQ is that it recognizes and examines the presence of guilt towards the donor, as well as feeling of responsibility towards caregivers or medical team¹⁰³— aspects unique to transplantation recovery and a useful tool for chaplains trying to gauge how a recipient is coping with transplantation and what areas of R/S coping may need to be addressed even if a formal spiritual assessment is not taken by the patient.

Hospital Anxiety and Depression Scale (HADS)

As is evidenced by its name, HADS is a 14 item, Likert style scale that used to detect anxiety and depression in people dealing with physical illnesses.¹⁰⁴ Specifically, HADS assesses

¹⁰⁰ Goetzmann *et al*, “Psychological Response and Quality of Life after Transplantation,” 477; J. P. Ziegelmann *et al*, “The Transplant Effects Questionnaire (TxEQ): The Development of a Questionnaire for Assessing the Multidimensional Outcome of Organ Transplantation — Example of End Stage Renal Disease (ESRD),” *British Journal of Health Psychology* 7, no. 4 (2002): 400-401, accessed April 10, 2020, <https://doi.org/10.1348/135910702320645381>.

¹⁰¹ Goetzmann *et al*, “Psychological Response and Quality of Life after Transplantation,” 478.

¹⁰² *Ibid*.

¹⁰³ Ziegelmann *et al*, “The Transplant Effects Questionnaire (TxEQ),” 402-403.

¹⁰⁴ Gurkan, Pakyuz and Demir, “Stress Coping Strategies,” 1393; Colleen L. Jay *et al*, “A Review of Quality of Life Instruments Used in Liver Transplantation,” *Journal of Hepatology* 51, no. 5 (2009): 952, accessed April 10, 2020, <https://doi.org/10.1016/j.jhep.2009.07.010>.

the patient's mood, interest level in activities, as well as symptoms of anxiety and panic that may be present.¹⁰⁵ HADS not only looks for signs of anxiety or depression, but it also looks at the severity of these symptoms in patients.¹⁰⁶ HADS was not developed for transplant-specific populations, but it has been shown to be a predictor of post-transplant psychosocial outcomes in recipients, and its indication of anxiety and/or depression would warrant further assessment for R/S distress as well.¹⁰⁷

Post-Traumatic Growth Index (PTGI) and Impact of Event Scale-Revised (IES-R)

Both the PTGI and IES-R tools evaluate aspects of trauma and its effects of healthcare patients, though not specifically related to transplant patients.¹⁰⁸ The PTGI seeks to specifically measure the amount of Post-Traumatic Growth (PTG) that a person experiences after the trauma, in this case transplantation, with PTG being described as "positive psychological changes in people who overcome trauma and show recovery over time from the traumatic event."¹⁰⁹ PTG is believed to serve as a cushion for people who have suffered trauma, such as undergoing a transplant, and allows them to find and return to stability.¹¹⁰ The PTGI contains 21 items that are divided into the 5 subcategories of: new possibilities, relating to others, personal strength, appreciation of life, and spiritual change.¹¹¹ The IES-R, designed by Weiss and Marmar, evaluates the level of trauma present in a patient by evaluating 22 items that assess the presence of hyper-arousal, intrusion, and avoidance.¹¹² Both the PTGI and IES-R are valuable tools for

¹⁰⁵ Jay *et al*, "A Review of Quality of Life Instruments," 952.

¹⁰⁶ Gurkan, Pakyuz and Demir, "Stress Coping Strategies," 1393

¹⁰⁷ Jay *et al*, "A Review of Quality of Life Instruments," 954.

¹⁰⁸ Jeon *et al*, "Post-traumatic Growth," 871-872.

¹⁰⁹ *Ibid.*, 871.

¹¹⁰ *Ibid.*

¹¹¹ *Ibid.*, 872.

¹¹² *Ibid.*

chaplains to gain a fuller picture of how a transplant patient is processing the transplant-related stressors, as well as how they are coping with the post-transplant consequences.

Summary

This chapter gave a detailed examination of the types of screening tools a chaplain can use to determine a transplant patient's risk for R/S distress. Commonly used spiritual screening tools include the COPE Inventory and its variations,¹¹³ and the Negative Religious Coping Scale (N-RCOPE),¹¹⁴ and the Rush Protocol.¹¹⁵ After assessing a transplant patient's R/S distress risk, it is also important for a chaplain to evaluate and consider the patient's coping with non-religious stressors that can significantly impact a patient's R/S coping. Assessments, such as the Transplant Effects Questionnaire (TxEQ),¹¹⁶ the Hospital Anxiety and Depression Scale (HAD),¹¹⁷ the Post-Traumatic Growth Index (PTGI),¹¹⁸ and the Impact of Event Scale-Revised (IES-R),¹¹⁹ provide chaplains with valuable insights into how the transplant patient perceives and copes with stressors so that a spiritual care plan can be formatted appropriately.

¹¹³ Jeremy P. Cummings and Kenneth I. Pargament, "Medicine for the Spirit: Religious Coping in Individuals with Medical Conditions." *Religions* 1, no. 1 (2010): 29-31, accessed April 2, 2020, <http://dx.doi.org.ezproxy.liberty.edu/10.3390/rel1010028>.

¹¹⁴ Cronjé *et al*, "Effect Of a Faith-Based Education Program," 94; King *et al*, "Determining Best Methods," 472.

¹¹⁵ Fitchett, Murphy, and King, "Examining the Validity of the Rush Protocol," 99; King *et al*, "Determining Best Methods," 472.

¹¹⁶ Goetzmann *et al*, "Psychological Response and Quality of Life after Transplantation," 477; J. P. Ziegelmann *et al*, "The Transplant Effects Questionnaire (TxEQ): The Development of a Questionnaire for Assessing the Multidimensional Outcome of Organ Transplantation — Example of End Stage Renal Disease (ESRD)," *British Journal of Health Psychology* 7, no. 4 (2002): 393–408. accessed April 10, 2020, <https://doi.org/10.1348/135910702320645381>.

¹¹⁷ Gurkan, Pakyuz and Demir, "Stress Coping Strategies," 1393-1394; Colleen L. Jay *et al*, "A Review of Quality of Life Instruments Used in Liver Transplantation," *Journal of Hepatology* 51, no. 5 (2009): 952-954, accessed April 10, 2020, <https://doi.org/10.1016/j.jhep.2009.07.010>.

¹¹⁸ Jeon *et al*, "Post-traumatic Growth," 872.

¹¹⁹ *Ibid*.

Chapter Four: Implications for Chaplains

As discussed in previous chapters, the entire process of transplantation—from screening, to wait listing, to the procedure, to recovery, and life-long implications—is a highly stressful process and has potential to cause life-long adverse reactions and R/S distress if not addressed. As such, chaplains have a responsibility and the opportunity to affect tremendous growth and healing in the R/S lives of transplant populations. This chapter will advocate several ways that chaplains can best work with transplant populations to promote growth and healing, to include how to utilize screening methods and various methods that are effective for ministering to the unique needs of the transplant population.

Screening for R/S Distress in Transplant Populations

Chapter 3 introduced several formal methods for screening for R/S distress, including how to evaluate a patient's coping styles. The only one of these that are specific to transplant populations is the TxEQ, and chaplains working with transplant populations should be familiar with this assessment tool and be comfortable using it to evaluate a patient's emotional and behavioral response to the five areas of worry, guilt, disclosure, adherence, and responsibility.¹²⁰ This tool, as well as the other previously discussed screening tools, can provide the chaplain with a baseline to guide their R/S assessment of patients, and would be especially helpful for new patients that the chaplain has not had the opportunity to spend time engaged in ministry of presence. Chaplains should be cautious, however, due to the self-reporting nature of these assessment tools and not rely solely on the assessments when creating R/S care plans. Self-

¹²⁰ See Appendix A for a sample TxEQ.

reporting assessments can only offer a general idea of how patients are coping with transplantation, and only as far as patients are aware of and willing to disclose their feelings.

It is for these reasons that it is critical that chaplains engage in intentional ministry of presence as the best form of R/S assessment. Ministry of presence is incarnational ministry in action—the chaplain chooses to spend time and build relationships with transplant patients and their caregivers. This relationship building allows the patient to come to trust the chaplain as a faith presence, or “a symbol of the presence of, and immediate availability of, God in [their] lives.”¹²¹ Through empathetic listening and inviting the patient into a non-judgmental space, chaplains have the opportunity to understand how the patient is coping, and assess areas of R/S need and how the patient may be open to exploring their R/S needs further with the chaplain. This incarnational ministry of presence also allows the chaplain to assess any needs that may need to be brought to the attention of the interdisciplinary team or may need referral to services that are beyond the capabilities of the chaplain to meet. As understood by Jueckstock and Vlach, this process enables the chaplain to hear unspoken messages within the patient’s stories and dialogue that help the chaplain gain an awareness of the patient’s spiritual state and needs that would be missed without investing time into this form of ministry.¹²²

Educating Patients Pre-Transplant

Not all transplant processes allow for pre-transplant educational opportunities, yet whenever it is possible and feasible pre-transplant education and preparation is beneficial for

¹²¹ Neil Holm, “Toward a Theology of the Ministry of Presence in Chaplaincy,” *Journal of Christian Education* 52, no. 1 (May 2009): 8, accessed July 3, 2020, <https://doi-org.ezproxy.liberty.edu/10.1177%2F002196570905200103>.

¹²² Joel A. Jueckstock and Kyle J. Vlach, “Claiming a Substantive View of Presence: The Significance of the Pastor’s Self,” *The Covenant Quarterly* 73, nos.3/4 (Aug/Nov 2015): 32, accessed July 3, 2020, <http://covquarterly.com/index.php/CQ/article/view/5>.

helping the patient achieve positive coping post-transplant. Studies show that transplant patients often do not feel they have been adequately prepared for the possible adverse reactions of transplantation prior to the surgery and without proper education the patient is less likely to have proper coping tools prepared.¹²³ As such, chaplains can advocate and provide for a program that educates pre-transplant patients on the effects a transplant can have on their R/S views and possible R/S distress symptoms to look out for, as well as provide coping tools and resources for the patients so they have resources to turn to in the event they experience any R/S distress post-transplant.

As examined in chapter two, poor coping styles are predictors for religious/spiritual distress among transplant patients. As such, pre-transplant educational attempts should include teaching patients, and their caregivers, positive and effective coping techniques to promote health and well-being after transplant. Research consistently demonstrates that active coping and acceptance of health circumstances promote higher levels of post-traumatic growth in patients.¹²⁴ Active coping entails employing adaptive strategies, such as recognizing problems, seeking appropriate and timely counsel, educating oneself about needs, and taking necessary steps to overcome challenges.¹²⁵ These are problem-focused techniques that correlate to better psychological outcomes, and thus is also helpful for R/S well-being.¹²⁶ Additionally, learning to use available support systems and resources is an effective way to promote positive coping with healthcare crisis and can give patients a sense of confidence in their ability to navigate their circumstances.¹²⁷ Studies conducted with kidney transplant patients showed that patients most

¹²³ Jones *et al*, "You Have Got a Foreign Body in There," 5.

¹²⁴ Perez-San-Gregorio *et al*, "Coping Strategies in Liver Transplant Recipients," 4-5.

¹²⁵ *Ibid.*, 5.

¹²⁶ Burker *et al*, "Religious and Non-Religious Coping," 514.

¹²⁷ Lindqvist, Carlsson, and Sjödn, "Coping Strategies of People with Kidney Transplants," 50.

commonly attributed optimist coping styles as the most effective strategies, and chaplains can carry this information over to their work with the wider transplant population.¹²⁸

One effective way to provide this is to set up a voluntary faith-based education program. Research consistently shows that faith, religion, and spirituality play an important function in one's response to illness and adversity and provide a buffering effect when there is a positive association with faith, religion, or spirituality.¹²⁹ In light of this, a chaplain's role is to provide a faith-based education program that addresses the most common reactions of transplant patients and how they effect a patient's R/S growth. This program should also teach ways to cope with the stressors of transplantation in a R/S healthy way. Faith-based education programs have demonstrated an ability to improve mental health functioning in ill populations, decrease the negative perception of disease or treatment, and provide a buffering effect for more than a year after participation in the educational program—all of these are reasons for chaplains to pour energy into developing and implementing a faith-based educational program for their transplant patients as early into the process as practical.¹³⁰

Addressing Spiritual Needs Post-Transplant

Just as during the pre-transplant period, chaplains should practice incarnational ministry with transplant populations. Transplant patients may expect the hard part of transplantation to be over with the successful completion of surgery,¹³¹ yet recovery and learning to live the rest of their lives as a transplant recipient bring many, often unexpected, challenges that chaplains can help patients navigate through their comforting presence. While it may seem as if the chaplain

¹²⁸ Ibid.

¹²⁹ Cronjé *et al*, "Effect of a Faith-based Education Program," 90.

¹³⁰ Ibid., 102-103.

¹³¹ Shuford, "The Spiritual Journey of an Organ Transplant Patient," 195.

isn't actively doing anything by simply being present during the patient's road to recovery, in reality the chaplain is participating in what Jueckstock and Vlach describes as "a dynamic relationship between divine and human action."¹³² This relationship happens when the chaplain leans on the Holy Spirit and trusts the Holy Spirit to use them as an agent of God's grace in the encounters with patients--walking through the triumphs and the challenges with a transplant patient as the hands and feet of Jesus.

Yet another valuable way to encourage R/S support and growth post-transplant is through peer support relationships. Transplant centers often have peer support groups that may be run by a center social worker, but the chaplain can encourage this process as a R/S tool as well. Specifically, chaplains ought to consider the benefits of connecting patients to another transplant patient that has shown post-transplant R/S growth and positive coping as way to encourage and mentor fellow transplant patients towards positive coping and their own R/S growth. Specifically, studies done with kidney populations have shown that peer support offers practical benefits, such as helping patients understand treatment and personal experiences related to treatments.¹³³

Peer support also provides emotional/psychological benefits of being able to talk to someone who truly understands what the patient is going through, finding encouragement, and gaining confidence that they could handle the challenges ahead because others have been able to.¹³⁴ There is much that can be gained when a patient feels they can relate to someone in regards to a situation that is as uncommon as undergoing transplantation, and while the interdisciplinary

¹³² Jueckstock and Vlach, "Claiming a Substantive View of Presence," 32.

¹³³ Jane Hughes, Eleri Wood, and Gaynor Smith, "Exploring Kidney Patients' Experiences of Receiving Individual Peer Support," *Health Expectations* 12, no. 4 (Dec 2009): 401, accessed July 18, 2020, <https://doi.org/10.1111/j.1369-7625.2009.00568.x>.

¹³⁴ *Ibid.*, 401-402.

team can help a patient understand and cope with the logistical and medical components of transplantation, it takes another transplant patient to empathize with how a transplant patient reacts to this challenging process. Chaplains can help identify, train, and connect successfully coping transplant patients as peer mentors or peer support systems when this approach would be appropriate and beneficial.

Another resource for addressing R/S concerns post-transplant involves connecting the patient to local clergy or faith-based support within the patient's community outside of the hospital. Many times, a transplant patient must travel a long distance to their transplant center, so long-term spiritual care may lie outside of the transplant chaplain's capabilities. As a result of the life-long nature of being a transplant patient, it is important that appropriate R/S care is encouraged after the patient is discharged from the hospital, and chaplains can facilitate this by reaching out to clergy within the patient's own community for resources and as a way to bridge a connection from the hospital to the patient's community. In situations when the patient already has a local faith-based community, the chaplain can ensure that the patient has the support in place prior to discharge, and when appropriate, can reach out to their clergy and offer to be additional support for the clergy and patient if future needs arise.

Addressing R/S Obstacles

After spiritual assessments, whether formal or informal, have been conducted chaplains should look for invitations to address any R/S obstacles that may be hindering a patient's growth and positive coping with transplantation. R/S obstacles, such as the presence of feelings of guilt and indebtedness, are risk factors that can be addressed by sharing what God's Word teaches on these subjects. The Bible has much to say about God's feelings on misplaced guilt and indebtedness, especially for those who have already placed their trust in Jesus Christ. When left

to fester, guilt and indebtedness can become obstacles to freely experiencing and living in the fullness of God's grace and truth. However, the chaplain has the opportunity to help struggling transplant patients to turn these obstacles of grace into opportunities to experience God's grace and can transform their post-transplant experiences.

The Apostle Paul teaches believers that, once we have salvation through Jesus Christ, there is no longer any condemnation for those who live under God's grace (Rom. 8:1). This sense of being free from condemnation carries with it connotations of salvation, but also of how believers are to live once they have been set free from their sin through justification in Christ Jesus. A quick look at the Greek translation of Romans 8:1 shows that the word used for condemnation is "katakrima,"¹³⁵ which refers specifically to the legal sentence and execution resulting from judgement.¹³⁶ In light of this understanding, believers can have confidence that they are not sentenced to any judgement of guilt and are free from the executing power of guilt over their lives. Transplant patients may feel guilty about their donor's death or sacrifice, in the case of living donors, but the circumstances that led to their donor's gift were not caused by the patient's need for a transplant and the recipient has no need to be weighed down by misplaced guilt, especially because no matter the cause of guilt feelings, God promises His children that they do not have to fear the judgement of guilt and the weight it carries.

Furthermore, God calls all believers to live in the abundant freedom bought through the blood of His Son, Jesus Christ. Again Paul, in his letter to the church in Galatia, instructs believers to "stand firm" in this freedom (Gal. 5:1), and this should be understood as a call to act

¹³⁵ Robert K. Brown and Philip W. Comfort, *The New Greek-English Interlinear New Testament* (Carol Stream, IL: Tyndale House Publishers, Inc., 1990): 551.

¹³⁶ Timothy Friberg, Barbara Friberg, and Neva F. Miller, *Analytical Lexicon of the Greek New Testament* (Victoria, BC: Trafford Publishing, 2005): 218.

on the freedom believers have in Christ, choosing each day to believe, think, and act as those who have been set free from the yoke of sin.¹³⁷ While feelings of guilt and indebtedness are common responses to transplantation, if a patient allows these feelings to hinder their relationship with God and others, or these feelings motivate the patient towards unhealthy coping mechanisms, they are standing in the way of a right view of God's grace and need to be addressed.

While chaplains have the whole of Scripture available to them for ministering to the needs of transplant patients, when patients are experiencing R/S distress especially related to guilt and indebtedness, using the principles found in Hebrews 4:16 are especially encouraging. Hebrews 4:16 simply states "Let us then with confidence draw near to the throne of grace, that we may receive mercy and find grace to help in time of need." From this simple verse, chaplains learn two important principles that should be applied to transplant patients dealing with guilt and indebtedness after their transplant. First, the Lord promises us that the patient who is a believer in Christ can approach God's throne of grace with confidence, or boldness as some translations renders the phrase.¹³⁸

Transplant patients need not fear that they are anything less than completely loved and accepted by God—the same God who knew they would need a transplant and allowed their donor to provide them with the gift of life. The gift of life is an altruistic decision each donor makes, and this selfless gift does not have anything to do with the worth or merit of the recipient, but is a personal decision of one person to help others in the event of their death. In other words, chaplains can gently remind recipients that because they didn't do anything to earn or deserve

¹³⁷ Tremper Longman III and David E. Garland, "Romans-Galatians," *The Expositor's Bible Commentary*, Rev. Ed. (Grand Rapids, MI: Zondervan, 2008), 620.

¹³⁸ Such as the *King James Version*.

their organ, just as they didn't do anything to earn or deserve God's grace, they can choose to accept the gift of donation in the nature in which it was given—freely and without strings attached from the donor. Organ donation is initiated as an act of love by the donor and, like God's free gift of salvation from sin, was the donor's prerogative. Acceptance of this knowledge can enable the recipient to embrace their new organ without strings and the heavy weight of guilt.

Secondly, Hebrews 4:16 teaches the transplant patient that when they seek the throne of grace, whether through prayer and petition, praise and worship, journaling, or reading God's Word, God will give them the mercy and grace they need to help them through their struggles. A word study of *we may receive* goes beyond an uncertain attainment, as the Greek word "labōmen"¹³⁹ is an active aorist verb that means to take hold of,¹⁴⁰ assuring transplant patients that when they seek mercy and grace to address their R/S distress, they will be able to take hold of both. Chaplains should encourage Christian patients to cling to these comforting truths and to actively pursue the grace freely given to all those in Christ Jesus.

Christian chaplains are called and commissioned to promote the R/S well-being of patients, and this is especially important with transplant patients. R/S spiritual well-being promotes healthy coping throughout healthcare experiences, and this same benefit has been demonstrated in transplant-specific populations.¹⁴¹ Religion is not only the most frequently coping resource,¹⁴² but it has also been shown that transplant patients with higher levels of

¹³⁹ Brown and Comfort, *The New Greek-English Interlinear New Testament*, 766.

¹⁴⁰ Friberg, Friberg, and Miller, *Analytical Lexicon*, 243.

¹⁴¹ Franco Bonaguidi *et al*, "Religiosity Associated with Prolonged Survival in Liver Transplant Recipients" *Liver Transplantation* 16, no. 10 (2010): 1158-1163, accessed April 2, 2020, <https://doi-org.ezproxy.liberty.edu/10.1002/lt.22122>.

¹⁴² Burker *et al*, "Religious and Non-Religious Coping," 514.

religious engagement have prolonged survival rates, post-transplant, than patients with lower levels of religious engagement in a study conducted in liver populations.¹⁴³ Understanding the positive potential impact of R/S assessment and intervention then, chaplains have an important role to play in the transplant population. It cannot be overstated then, that R/S assessment and intervention must happen throughout the entire lifespan of the transplant process—from evaluation, to the waitlist period, to post-transplant hospital recovery, to long-term R/S care from discharge forward.

Summary

The highly stressful nature of the transplant process dictates that chaplains be proactive and intentional in their ministry to the transplant population. Chaplains should screen for R/S distress risk factors early, thoroughly, and diligently while seeking signs that patients are struggling with any of the discussed stressors and risk factors for R/S distress. Chaplains should use both formal assessments, as discussed in previous chapters, as well as incarnational ministry—compassionately walking through the transplant process with their patients. Chaplains are to be the hands and feet of Jesus Christ to those who are hurting and walking through some of the darkest moments of their lives, in order to bring true peace.¹⁴⁴

Chaplains should also advocate for patient education prior to transplantation. Much like transplant patients must have education on their post-transplant physical care, transplant patients

¹⁴³ Bonaguidi *et al*, "Religiosity Associated with Prolonged Survival," 1161.

¹⁴⁴ Tracy A. Balboni, and Michael J. Balboni, "The Spiritual Event of Serious Illness," *Journal of Pain and Symptom Management* 56, no.5 (2018): 818, accessed April 10, 2020, <https://doi.org/10.1016/j.jpainsymman.2018.05.018>; Ana Amélia Machado Duarte *et al*, "Spirituality and Religiosity are Associated with Quality of Life in Patients with Lung Disease," *Journal of Religion and Health*, 11(2018): 7, accessed April 2, 2020, <http://ezproxy.liberty.edu/login?url=https://search-proquest-com.ezproxy.liberty.edu/docview/2136318908?accountid=12085>.

also need to be able to learn effective R/S coping tools and be able to view their transplant process through a R/S lens. Transplant patients have reported that they were not adequately prepared for the adverse reactions to transplantation prior to the surgery, and thus did not have positive coping tools prepared.¹⁴⁵ One of the ways to combat this feeling of being ill prepared is to provide encouragement and education from fellow transplant patients that have coped with their transplant in positive ways, as well as to offer a faith based education program for patients that desire to explore the R/S ramifications of transplantation.¹⁴⁶

After transplant has taken place, R/S needs should be assessed and addressed when appropriate and necessary.¹⁴⁷ This can be accomplished through incarnational ministry—spending intentional time with the transplant patient, building trust with them, and allowing them to share their hurts and fears without judgement or censorship—meeting the patient where they are in the coping process while extending God’s grace, love, peace, and hope to them. Peer support and connecting the transplant patient with a local faith-based community (if they do not already have one) are also important resources for addressing R/S distress.

When R/S distress is present, especially when there are obstacles to God’s grace such as guilt and indebtedness present, the chaplain should look for invitations to share God’s truth with the patient. The Bible has much to say about God’s feelings on misplaced guilt and indebtedness, especially when someone has already placed their lives and souls into the hands of Jesus Christ.

¹⁴⁵ Jones *et al*, "You Have Got a Foreign Body in There," 5.

¹⁴⁶ Cronjé *et al*, "Effect Of a Faith-Based Education Program."

¹⁴⁷ S. Kannan and S. Gowri, "Spiritual Care: Define and Redefine Self," *Journal of Religion and Health* 59, no. 1 (2020): 470-483, accessed April 2, 2020, <https://doi-org.ezproxy.liberty.edu/10.1007/s10943-016-0269-9>; I Milaniak *et al*, "Relationship Between Types of Social Support, Coping Strategies and Depression in Heart Transplant Recipients," *Journal of Heart and Lung Transplantation* 34, no. 4 (April 2015): S313–S314, accessed March 22, 2020, <https://dx.doi.org/10.1016/j.healun.2015.01.886>.

Believers in Jesus Christ are set free from all guilt, shame, and debt—Christians are called to walk in the freedom of God’s grace, bought through the blood of Jesus Christ (Rom. 8:1; Gal. 5:1; Heb. 4:16). Just as no one can repay Jesus Christ for His sacrifice on the cross or even be worthy of such a gift, transplant patients should be encouraged to consider that they were not given their new organ because they deserved it more than others, or because they need to repay their donor. Transplant recipients were given their new organ because someone wanted to freely give their organs to save others when they could no longer use them themselves,¹⁴⁸ therefore guilt over organ transplantation is as misplaced as God says our continued guilt is for someone born again in Christ Jesus.

Research has long shown that R/S health promotes coping through healthcare experiences and crises, and transplantation shows the same benefit from R/S coping.¹⁴⁹ R/S coping has been shown to decrease negative health risks, such as depression and anxiety,¹⁵⁰ as well as increasing overall perception of quality of life, which leads to better medical adherence and decreases risk of transplant failure due to non-compliance.¹⁵¹ Armed with this knowledge, combined with an acute awareness of the unique risk factors of transplant patient R/S distress and coping, long-term evaluation and follow-up is called for to ensure long-term positive coping and treatment of R/S distress.

¹⁴⁸ Elizabeth Parr and Janet Mize, *Coping with an Organ Transplant: A Practical Guide to Understanding, Preparing for, and Living with an Organ Transplant* (New York: Penguin Putnam Inc., 2001), 110.

¹⁴⁹ Bonaguidi *et al*, "Religiosity Associated with Prolonged Survival," 1158-1163.

¹⁵⁰ Cronjé *et al*, "Effect Of a Faith-Based Education Program," 102.

¹⁵¹ Bonaguidi *et al*, "Religiosity Associated with Prolonged Survival," 1158.

Chapter Five: Steps Forward

Additional Screening Efforts

Chaplains have the opportunity to participate in future efforts to decrease R/S distress experienced by transplant populations and promote efforts to build positive coping in this unique population. As this paper has shown, there are existing screening tools available for use with transplant populations, but the majority of them are not transplant-specific and there needs to be much research and development done to promote even better understanding of how transplant patients cope, and how transplantation specifically effects the R/S functioning of recipients of both cadaveric and living donors. Due to perceived societal expectations, current research findings may be skewed by self-reporting being influenced by patients conforming to these societal expectations of downplaying or hiding reactions viewed as inappropriate or unacceptable.¹⁵² Developing R/S assessments that take this awareness into account would benefit the spiritual care ability for the transplant community. Chaplains that work with transplant populations should use the knowledge gained through their incarnational ministry approach to assist in the formation of these formal assessment tools.

Post-Transplant Follow-Up

As repeatedly stated, once someone is a transplant patient, they are a transplant patient for the rest of their lives. The R/S consequences and effects of transplantation can linger for years and may have to be addressed more than once if growth is to be promoted. With these possibilities in mind, chaplains are encouraged to continue to conduct R/S assessments periodically throughout the post-transplant period, not just while in the hospital during initial

¹⁵² Goetzmann *et al*, "Psychological Response and Quality of Life after Transplantation," 481.

recovery. This may be done through formal assessments conducted over the phone or even via e-mail, when applicable and appropriate, with the patient's permission. If the patient is able, participation in a long-term peer support group or network can also be beneficial for monitoring the patient's R/S well-being long-term when the chaplain is able to participate in/observe these support groups as well. While the transplant medical team is focused on the health of the transplanted organ, it is the chaplain's responsibility to promote the R/S health of the transplant patient for as long as they are part of the chaplain's care group.

Improved Holistic Patient Education Programs

Transplant patient education programs currently focus on pre-and post-transplant medical, nutritional, and financial education. While these are priorities of transplant preparation to ensure the patient and caregiver are able to comply with transplant protocol and better ensure successful transplantation, these are not the only important aspects of coping with transplantation. R/S education should be incorporated into any transplant education program, both before and after transplantation takes place. As already demonstrated, research consistently shows that religious engagement promotes healing, increases survival rates, and is a buffer against mental health complications, such as depression. Considering these benefits, why is R/S well-being not addressed in the transplant educational programs? While patients should not be mandated to take R/S educational programs as part of the transplant process, R/S well-being programs should be offered to every transplant candidate that wishes to explore this area of transplant coping. R/S care would benefit from faith-based educational programs being available for patients throughout the transplant process and can be conducted in either group or individual sessions—by the chaplain, a trained lay volunteer, or even a trained transplant peer mentor.

Summary

The future of spiritual care for the transplant patient population calls for the development of additional R/S distress screening methods that are specifically geared towards screening for risk factors prior to transplantation, as well as identifying the true level of negative R/S coping being experienced by transplant patients by decreasing the risk of responses that may be skewed by social expectations or conventions. Holistic post-transplant care involves the R/S needs of the transplant patient in addition to the medical follow ups that take place throughout the course of the life of the transplant patient's post-operative care. Finally, improved patient education, such as a faith-based education model, would prepare transplant patients for the myriad of emotions and experiences that they may struggle with after transplantation and thus better equip transplant patients for positive coping.

Conclusion

This thesis sought to examine how the unique challenges faced by transplant patient populations contributed to R/S distress. Chapter one introduced the non-religious stressors that are common to transplant patients, including physical, emotional/psychological, financial, relational, and vocational. Chapter two examined risk factors for spiritual distress in transplant patients that have a R/S aspect—guilt, indebtedness, and poor coping of transplant-related stressors were all found to increase the risk for R/S distress during the transplant process. Chapter three was a brief introduction to commonly used screening tools used to assess R/S well-being and evaluate a patient's state of coping, with only the TxEQ being solely for transplant specific populations.

Chapter four suggested implications for chaplains working with transplant patient populations, including how to use incarnational ministry in both screening and addressing R/S distress. Chapter four also suggested ways faith-based education programs could benefit patients both proactively and after R/S distress is detected. Finally, chapter four examined a Biblical response to feelings of guilt and indebtedness and how chaplains can turn these potential obstacles to grace into opportunities for transplant patients to fully experience God's grace and mercy. Chapter five proposed steps forward for healthcare chaplains that work with transplant patients, especially as it concerns the need for more transplant-specific screening tools, post-transplant follow-up spiritual care, and advocated for the need for R/S education programs to be made available to transplant patients from the beginning of their transplant journey. Chaplains have an important role to play in helping patients fully recover and thrive in their post-transplant lives, and this paper sought to demonstrate some ways chaplains can accomplish this.

Appendix A: TxEQ Example¹⁵³

* all items are answered on a 5-point Linkert scale “ranging from ‘strongly disagree’ to ‘strongly agree’ (scored from 1 to 5)”¹⁵⁴

Factor 1: ‘worry about transplant’

- I am worried about damaging my transplant
- With regard to my transplant I feel that I am carrying around something fragile
- I am hesitant to engage in certain activities because I am afraid of doing harm to my transplant
- I keep wondering how long my transplant will work
- I monitor my body more closely than before I had the transplant
- I worry each time my anti-rejection drug regime is altered by my doctor

Factor 2: ‘guilt regarding donor’

- I feel guilty about having taken advantage of the donor
- Sometimes I think that I have ‘robbed’ the donor of a vital part
- The donor had to suffer to make me feel better
- I have the feeling that the donor/the donor’s family has some control over me
- I do not have any feelings of guilt toward the donor

Factor 3: ‘disclosure’

- I avoid telling other people that I have a transplant
- I am uncomfortable with other people knowing that I have a transplant
- I have difficulty in talking about my transplant

Factor 4: ‘adherence’

- Sometimes I do not take my anti-rejection medicines
- Sometimes I forget to take my anti-rejection medicines
- When I am too busy I may forget my anti-rejection medicines
- Sometimes I think I do not need my anti-rejection medicines
- I find it difficult to adjust to taking my prescribed anti-rejection drug regime

Factor 5: ‘responsibility’

- I think that I have a responsibility to the transplant team to do well

¹⁵³ Ziegelmann *et al*, “The Transplant Effects Questionnaire (TxEQ),” 400-401;

¹⁵⁴ *Ibid.*, 398.

-I think that I have a responsibility to my friends and my family to do well

-I feel that I owe the donor/the donor's family something that I will never be able to repay

-I think that I have a responsibility to the donor/the donor's family to do well

Appendix B: Thesis Approval Sheet

RAWLINGS SCHOOL OF DIVINITY

GRADE

THESIS MENTOR

Dr. Harold D. Bryant

READER

Dr. Donald Q. Hicks

Appendix C: List of Definitions

Cadaveric Donor: An organ donor that has died and has met criteria to become an organ donor.

Guilt: the feeling or conviction that the individual is responsible for the death of the organ donor, i.e., thoughts like “Someone else had to die so that I could live.”

Immunosuppressive Therapy: medical regimen used to suppress the transplant patient’s immune system to prevent organ rejection post-transplant.

Indebtedness: A feeling of obligation or responsibility to repay the organ donor or donor’s family by the organ recipient that can become an adverse reaction because there is no way to repay someone who is no longer alive, and the transplant recipient will likely not even know who their donor was due to confidentiality policies in the transplantation process.

Living Donor: An organ donor that is still living and is approved to donate all or a portion of an organ to someone needing that organ; can be related, known, or unknown to the recipient.

Recipient: The person that receives the donated organ for transplantation; the transplant patient.

Religious/Spiritual Distress: For the purposes of this thesis, religious/spiritual distress is defined as any adverse or negative reactions, thoughts, or feelings related to the individual’s understanding of their religious or spiritual convictions, including (but not limited to): their understanding of, relating to, or relationship with a transcendent other (such as God or other) or practice of their preferred religion/spirituality/faith.

Appendix D: List of Abbreviations

UNOS: United Network for Organ Sharing

R/S: Religious/Spiritual

N-RCOPE: Negative Religious Coping Scale

TxEQ: Transplant Effects Questionnaire

HADS: Hospital Anxiety and Depression Scale

PTGI: Post-Traumatic Growth Inventory

IES-R: Impact of Event Scale-Revised

IV: Intravenous Therapy

PTSD: Post-Traumatic Stress Disorder

IS therapy: Immunosuppressive Therapy

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