Introduction

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Organ transplantation aims to extend lives, improve quality of life, and deliver hope to many patients and their families. However, the path to transplantation is fraught with angst and challenges. Failing health is usually associated with changes in social (e.g., loss of work, loss of status), interpersonal (e.g., change in relationships, loss of activities), and psychological (e.g., anxiety, depression, panic attacks) struggles.

There are numerous emotional, behavioral, and psychological aspects to organ transplantation, and psychiatric consultants have been involved with the transplantation process since its inception. In fact, Richard Herrick, the first successful kidney recipient, experienced an episode of delirium just before his transplant surgery, causing concern to his providers and complicating his care. Dr. Joseph Murray, the pioneer plastic surgeon turned transplant surgeon, described this dramatic episode in his autobiography *Surgery of the Soul* [1]. Richard Herrick was admitted to the Peter Bent Brigham Hospital on October 26, 1954, with chronic nephritis. Dr. Murray described the clinical challenges the patient and his medical team experienced due to "Richard's difficult behavior as a result of his illness." He borrows the following excerpts from Richard's medical record [1]:

> Since admission patient has been extremely uncooperative. Has knocked over infusions, has been restrained, has been moved to side room because of loud outbursts. Restless, cursing all members of the House Staff…
> Rather a difficult p.m. … Is extremely uncooperative. Behavior erratic and unpredictable. Bit nurse on hand while bed linen being changed…

The consulting psychiatrist who evaluated and treated the patient subsequently reported [1]:

> …[Prior] to dialysis, patient showed a varying disorientation as to time, place, and person… During his excited stages he would pull out his indwelling urethral catheter and would struggle against doctors and nurses, accusing them of attacking him sexually. Impression: toxic psychosis reaction superimposed on a paranoid personality. Offhand, I feel the patient will recover from his psychosis with the use of medications and removal of toxic agents by dialysis…

The behavioral and cognitive changes experienced by this famous patient are very familiar to the mental health professionals of today, who consult and assist transplant teams in the care of patients during the peri-transplant process. Today, we know that cognitive dysfunction and delirium pre- and post-transplantation are not only common but can adversely affect post-transplant clinical outcomes. Several studies have been done on liver and lung transplant patients demonstrating that pre-transplant cognitive impairment is associated with worse post-transplant cognitive status and survival, while post-transplant delirium is associated with longer ventilation times, hospital stays, and potentially increased mortality [2–7].

In Dr. Murray's account, the psychiatric consultant also played a pivotal role in conducting the first live donor psychosocial evaluation, highlighting the ethical considerations as to whether the team should proceed with surgery in a healthy individual to remove a kidney to assist his ailing brother [1].

Emotional challenges and setbacks have influenced and determined the pre- and post-transplant course of many end-stage organ failure patients. Studies have found a high prevalence of pre-transplant anxiety and depression among these patients [8–14]. Significant correlations between preoperative psychiatric diagnoses and poor medical adherence [15, 16] as well as between the presence of various psychosocial factors and postoperative coping and social support [17] have been demonstrated. Over a quarter of solid organ transplant recipients experience depression and/or anxiety after transplant, and the occurrence of depression and anxiety affects post-transplant medical outcomes [18–32]. Indeed, studies have demonstrated that many pre-transplant

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psychosocial problems continued after transplantation and that psychiatric challenges after transplantation led to a higher risk of infections, hospital readmissions, and higher medical costs [30]. Moreover, specific psychosocial variables are significantly associated with shortened post-transplant survival [18, 33, 34]. Finally, substance use disorders may profoundly affect both the pre- and post-transplant outcomes [16, 35–41]. Psychosocial consultants may thus assist not just in the assessment but in developing a treatment plan and process to help patients achieve the utmost success.

In some cases, the psychological influences affect patients just as much as physical complications do. In her book *I'll Take Tomorrow,* Mary Gohlke, the courageous woman to undergo the first successful heart-lung transplant at Stanford, frankly described and shared her illness and emotional journey and the post-transplant challenges [42]. In her book, Mrs. Gohlke takes the readers through the whole array of the tumultuous psychological and psychiatric experiences associated with the pre- and post-transplant course. She shared the incredible aloneness she felt while sick and dying before the transplant, deteriorating due to advancing pulmonary hypertension. She described the courage and determination she had to master in order to keep fighting and taking a chance with an experimental endeavor, a lung-heart transplantation, to go on living. During the post-transplant period, she had to struggle with postoperative delirium likely due to steroid-induced psychosis, the burden of multiple immunosuppressant agents, the surgery itself, and renal insufficiency. She described feeling confused, irritable, and paranoid during her delirious state, which affected not only her but her primary social support, her husband. She experienced demoralization for not getting stronger fast enough; frustration for being stuck in the hospital; and exasperation at the daunting task of getting better [42].

After she left Stanford hospital, she experienced a whole host of emotional disturbances, including panic attacks and a debilitating anxiety. For a period of time, she became paralyzed with anxiety, terrified to leave her newly established safety net. Life was different, she was different, and she had to find her new balance and confidence. She acknowledges the invaluable assistance she received from the transplant team's consulting psychiatrist. Later after returning home to Arizona, she developed depression: not only did she not enjoy many activities and lacked concentration and motivation, but she could not gain much needed weight due to her lack of appetite. Again receiving psychological help was paramount to her ability to gain weight and continue with success. Although Mary Gohlke frequently bemused in her honest and straightforward memoir of why people reached out to her commending her courage to undergo this experimental at that time surgery, her courage indeed must be commended: not only for undergoing the surgery, surviving, and sharing her story with the world, but also for such honesty sharing her emotional experience.

Transplantation has revolutionized what patients with end-stage organ disease can imagine for themselves. The transplantation field has had many firsts and will undoubtedly continue to develop. It has been built by many talented, courageous, brilliant, and determined people: scientists, immunologists, pathologists, surgeons, physicians, mental health professionals, and, of course, the brave individuals and their families who have donated organs for those in need.

As described above, the first successful renal transplant occurred in 1954 in Boston, USA [1, 43]. The first successful liver transplant took place in 1967 in Denver, USA [43]. The first successful heart transplant took place in 1967 in Cape Town, South Africa [43]. The field was revolutionized by the discovery of cyclosporine, an immunosuppressant, in the 1970s in Switzerland [43]. The first successful heart-lung transplant took place in 1981 at Stanford, USA, as narrated by Mary Gohlke in her book [42, 44]. The first successful long-term single-lung and then double-lung transplant occurred in Toronto, Canada, in 1983 and 1986, respectively [44]. The year 2005 saw the first successful partial face transplant in France [45], and 2011 welcomed the first double-leg transplant in Spain [46].

These firsts have allowed thousands of people to live longer lives, have better quality of life, and discover new hope. However, with these growing opportunities, increasing demands follow. In the United States, every 10 minutes, someone is added to the national transplant waiting list [47]. As of April 15, 2018, 114,807 patients with end-stage organ failure are on the national waiting list in need of a life-saving transplant [48]. The demand much outweighs the supply of donated organs, and on average 22 people die each day waiting for the organs [48]. The psychosocial strain and distress that all of these patients experience throughout their transplant and life journeys are significant.

This is where psychosocial consultants (i.e., transplant mental health clinicians, social workers, psychologists, and psychiatrists) can make a difference. The psychosocial team can enhance the candidate selection process by fine-tuning the assessment of patients being considered for transplantation. They play an important role in the overall transplant theater: improving outcomes, survival, and the quality of life of transplant patients and their families. They play an integral part assisting the rest of the transplant team in caring for the inevitable cognitive and behavioral complications of organ dysfunction, both before and after the transplant surgery. And

they have an indispensable role addressing the psychological and emotional reactions when life expectancy is threatened, when hope is taken away. These are the times psychosocial consultants are most needed, and their participation can make a unique difference, helping teams to take care of the whole person and assisting patients to make sense of their experiences and find meaning in their lives. Patients, as all of us, crave witnesses to their lives. We can be that witness.

We are profoundly grateful to many who taught us, mentored us, and served as pioneers and role models in transplantation psychiatry. Multiple articles have been written and quoted throughout this book. Several books have been published regarding the psychosocial aspects of transplantation. For instance, Drs. Paula T. Trzepacz and Andrea F. Dimartini edited an excellent textbook covering the biological, psychological, and ethical considerations in organ transplantation in 2000 [49]. Their work and that of the mental health professionals who tirelessly strive every day to improve the life of transplant patients has served as an inspiration to this volume.

What we envisioned in this textbook is an up-to-date, comprehensive, evidence-based guide to our transplant colleagues for the multidisciplinary psychosocial care of end-stage organ disease and transplant patients. To assist in the process of caring for our transplant patients in the most knowledgeable, collaborative, and compassionate way, we need to understand the underlying end-stage organ disease process; the details of transplantation; the prognosis and possible complications after surgery; the neuropsychiatric complications of organ failure; and the complex immunosuppressive medication regimen, associated neuropsychiatric effects, and interactions with other medications. We need to be aware of the expectations of our patients, their families, and the rest of the medical team. We need to understand the complex psychological reactions experienced by patients who face extraordinary medical challenges. Of course, above all, we need to understand our patients as people with their unique life experiences, goals, and values.

Our hope is that this book will offer a comprehensive starting point for mental health professionals working with this complex patient population through their incredible medical journeys. This book is also intended to assist medical professionals working with end-stage organ disease and transplant patients, by providing a wider glance into their patient's psychological world, and thus offering an opportunity to appreciate the implications of mental health for their overall wellbeing.

This book is organized into several parts. Several sections are based on organ systems (i.e., kidney, liver, heart, lung, visceral, and hematopoietic cell transplant) and include chapters on pre-transplant medical indications, pre-transplant psychosocial and psychiatric concerns, history of respective transplantation field, post-transplant medical course and complications, post-transplant psychosocial and psychiatric care considerations, and some special subjects (e.g., dialysis in renal patients, extracorporeal membrane oxygenation (ECMO) in lung patients). Other chapters are dedicated to topics such as vascularized composite transplantation, pediatric populations, substance use disorders, psychopharmacology, psychotherapy, palliative care, ethics, and cultural factors.

This book contains contributions from specialists that span the entire spectrum of transplant care (e.g., psychiatrists, psychologists, medical subspecialists, surgeons, dieticians, social workers, and ethicists). The voices reflect their specific expertise and experiences, but as they do every day in clinics and hospitals, across the globe, these experts have come together in this book to share their expertise and wisdom. However, in this book, the most treasured voice is that of those who themselves have gone through the transplant process, our patients. These writers have generously shared their very personal journeys with us, reflecting on their unique emotional experiences. They are our best teachers.

It has been an honor to put this book together, and we hope that it will continue to advance the care of end-stage organ disease and transplant patients.

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