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Introduction

Transplant mental health clinicians routinely evaluate, diagnose, and treat mood, anxiety, and substance use disorders in patients pre- and post-transplantation. However, these psychological problems do not fully encompass the totality of the experience of someone facing a serious medical illness, and transplant patients frequently bring in concerns beyond the diagnosable mental health disorders neatly categorized by the DSM5. Being evaluated for and/or surviving and living after transplantation means that the person has faced their own mortality and they continue to live with a chronic medical condition, facing an uncertain future. For many people, the themes of death and dying, meaning of life, individual freedom versus dependence on others, loss of dignity, change in relationships and roles, and life legacy become integral components of their journey, especially during the waiting period for transplantation, challenging post-transplant recovery, and/or when facing new complications and post-transplant deterioration. These are all existential concerns, stemming from our contemplation of our existence and its limitations, marked by our mortality. Existential distress brought on by these concerns has been studied in oncology patients and palliative care settings [1–3]. However, a search for articles combining the themes of “existential distress” and “transplantation” produces almost no articles on solid organ transplant candidates or recipients [4]. Yet, existential distress is common in patients facing significant medical challenges. In fact, 30 to 50% of cancer survivors report existential concerns due to the uncertainty, a sense of uncontrollability and difficulty incorporating the cancer experience into their identity [2]. In a study of 164 adults with cystic fibrosis (CF), a genetic life-shortening disease, which frequently leads to the need for lung transplantation (and at times, liver transplantation), authors identified significant

unmet existential needs, with most frequent ones being fears about CF worsening (50%) and uncertainty about the future (39%) [5]. A descriptive study of Irish patients with kidney failure receiving outpatient hemodialysis either awaiting a kidney transplant or an evaluation for a transplant also described existential concerns brought on by the experience of living with a deteriorating medical condition while being on dialysis and considering transplantation [4]. These concerns included uncertainty and anxiety waiting for a transplant, living in a limbo and inability to plan for the future, and overcoming distressing existential moods [4].

Similarly, in the collective clinical experience of transplant mental health clinicians, transplant candidates and survivors both struggle with feelings of loss and grief in the context of medical illness cutting short their expected life experiences, difficulty incorporating their transplant experiences into their identities, relationship and life role changes, searching for meaning behind their challenging experiences, feeling as if they are living on borrowed time, or yet again directly facing mortality when they develop new complications and organ/graft failure. This chapter further explores these themes by describing a case of a lung transplant recipient facing chronic rejection and existential themes brought on by his deterioration.

Case History

Mr. A was a 48-year-old man with interstitial lung disease who underwent lung transplantation 5 years ago. Unfortunately, his course was now complicated by bronchiolitis obliterans syndrome (BOS), a form of chronic rejection, and he experienced declining lung function with associated shortness of breath, reduced endurance, and increased fatigue, requiring increasing amounts of supplemental oxygen. Mr. A was found not to be a candidate for re-transplantation due to significant scarring in his chest cavity. He was now referred to a transplant psychiatrist, with whom he had worked with early on after transplantation, for

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what the transplant team thought were worsening symptoms of depression.

Mr. A described feeling sad about his yet again experiencing declining health. After his transplantation 5 years ago, he had been hopeful about longevity, but was also painfully aware that the median survival for lung transplant recipients was indeed 5 years. Now with worsening chronic rejection, his symptoms were similar to his initial symptoms of end-stage lung disease and the patient shared his associated grief and fear. Mr. A. understood his condition and although his immediate prognosis was not clear, he knew that he was irreversibly declining. Mr. A was particularly sad about leaving his wife of 20 years and their three children behind. His older daughters were 25 and 22 years of age and thus more established, but he felt sad about his younger daughter, who was only 13 years. He was concerned about the financial well-being of his family after his is gone. He wanted to be remembered by his family, but he did not want his wife to spend her life mourning him. He felt sad and disappointed that he would not be there with her into her old age, and he did not want her to be alone. He also felt disappointed that his winemaking business did not take off as he had envisioned it. In addition, he expressed guilt of putting more burden onto his wife and older daughters to take care of him and the household.

In addition to feeling these losses, Mr. A was scared about the actual experience of further deterioration and dying. He had a complicated recovery after his lung transplantation, having spent many days in an intensive care unit on the ventilator and he did not want to be intubated again if it would not lead to his recovery. He was also anxious about what dying would be like and of course did not want to suffer. At the same time, he was unsure about the afterlife.

Mr. A and the psychiatrist spent time processing all of these important and valid concerns. It was important for Mr. A to have an open and supportive space to speak about his feelings and thoughts and feel validated. He was able to work through his grief and accept the life that he had lived so far. He was able to re-frame his feelings of being a burden on his family into gratitude for their presence and support. He was able to appreciate that his legacy would continue with his daughters, especially since one of them was learning winemaking after being inspired by him. He also was able to appreciate that his family will be financially secure with his wife's income and provisions he would leave behind for them. He told his wife to re-marry after his death and decided to write a series of letters for his younger daughter for important occasions in her life.

The psychiatrist and Mr. A also discussed what dying might look and feel like; this enabled patient to further discuss his end-of-life goals and code status with his transplant team. Patient was referred to the palliative care team to address any physical symptoms at this point of his condition and to provide additional structural support to him and his

family. Additionally, Mr. A was able to reintegrate his faith into his overall experience. He was still unsure about the afterlife, but expressed that he "was curious and excited to find out what happens after." While he felt sad about his early death, he was able to express that he had lived his life the best he could and to focus on the small joys left to him: spending time with his family, eating a few meals, and sitting outside in his garden. Eventually, he was enrolled in an outpatient hospice program who managed his worsening dyspnea due to progressive respiratory failure. The psychiatrist discussed dignity therapy with the patient and Mr. A was very enthusiastic about doing it. Unfortunately, patient was not able to return to his outpatient psychiatry appointments due to his now quickly deteriorating state. He died peacefully at home surrounded and supported by his family.

Clinical Questions

1. What existential themes are brought up in context of transplantation?
2. What psychological interventions are available to psychiatrists working with transplant patients struggling with existential distress?
3. What practical interventions are available to psychiatrists working with transplant patients struggling with existential distress?

Discussion

While research on existential themes and existential distress specifically in transplantation is lacking, the available literature in the fields of psycho-oncology and palliative medicine provides an excellent blueprint to be applied to similar issues in transplantation medicine.

When discussing working with patients facing their mortality, Kissane expands on Yalom's work and lists major sources and categories of existential distress: (1) death anxiety, (2) loss and change, (3) freedom and autonomy, (4) dignity of the self, (5) fundamental aloneness, (6) altered quality of relationships, (7) meaning, and (8) mystery [6]. Many of these themes come up for transplant candidates and recipients. Patients are appreciative and reassured when mental health (and medical) providers are able to connect to this experience, normalize it, and help patients process these difficult, yet very human and common, experiences, and emotions. Breitbart summarizes the existential literature and elaborates further: he explains how as humans aware of our existence, we feel compelled to respond to this existence with creating our own unique meaning and living out our lives to the best of our potential [7]. But since we all invariably fall short of these expectations at some point in our lives, we are bound to experience *existential guilt*, the sense of "I should have done more" [7]. Breitbart states, "In the

clinical setting, existential guilt is manifest when the arc of the trajectory of a patient's life has been knocked off course by an obstacle, a limitation, cancer, the loss of roles, the proximity of death. The larger the delta between the idealized trajectory and the one that has unfolded is proportionate to the existential guilt experienced." [7] Transplant candidates or recipients, who might be living with a chronic deteriorating medical condition or acutely decompensate, younger or older, are eventually aware of their impending mortality, associated losses, and grief. Patients might grieve the loss of their career or never having children or not having the retirement and dignified old age the way they imagined and hoped for. Mr. A was grieving the loss of his hopes to live out his life with his wife into their elderly years and to be there for his daughters. He fell short of his expectations to raise his younger daughter and to further establish his wine-making business. An important intervention was to allow Mr. A the opportunity to express his sadness, grieve these losses, accept them, acknowledge that he did the best he could, and then allow him to plan how to care of his loved ones even after he was gone. Mr. A did this by voicing to his wife that he wants her to eventually re-marry, leaving letters for his younger daughter, and appreciating that his family will be financially stable after he is gone.

Appreciating the sources of existential distress and creating space for patients to acknowledge it can be very powerful. In addition, several existential therapies exist to particularly speak to this experience and help patients transform it and find solace and meaning. While none of these have been specifically studied in transplant candidates or recipients, evidence from other chronically ill communities may be extended to this patient population. Existential psychotherapy, built on the ideas of Victor Frankl and Irv Yalom, aims to address questions about existence and to understand and ease patients' anxiety when facing questions about mortality. It is imperative for patients to have a witness and a partner in their medical journey not only as a patient but also as a human, and as a "fellow traveler," the mental health clinician can support the transplant patient confronting anxiety in the setting of death, isolation, and emptiness inherent in one's suffering [8]. They can help the patient focus patient on making choices and decisions based on their responsibilities and deriving meaning from their experiences [8].

Other, more structural existential psychotherapies, traditionally developed for end-of-life patients, offer important themes that likely can be integrated throughout the chronic disease continuum and experience of transplantation, while particularly poignant at end of life. Meaning-centered psychotherapy, developed by Dr. William Breitbart at Memorial Sloan Kettering Cancer Center for advanced cancer patients struggling with despair, hopelessness, and desire for hastened death, was initially introduced as a group therapy (8 sessions) for demoralized patients with limited prognosis and later adapted for individual sessions (7 sessions) [8, 9]. The ther-

apy aims to bring meaning to patients' lives via helping them to consider attitudes toward life and death, connecting with life through love, art, humor, nature, and relationships; engaging with life through creative pursuits; and developing a deeper understanding of their identity and legacy [9].

Another form of structured existential therapy is dignity therapy, developed by Dr. Harvey Chochinov for patients nearing death, focusing on the production of a "generativity document" and aiming to maximize the dignity conserving practices and perspectives of the patient [10, 11]. It has been studied in terminally ill patients, cancer patients, and patients with Huntington's disease, but not in transplant patients. We recently published a case report of modified dignity therapy (prolonged over several months) in a patient with CF who declined lung transplantation [12]. This therapy is most appropriate for patients nearing terminal situations, but is at least 2 weeks away from their predicted death. However, as in the case report above, themes and strategies can be extrapolated beyond the traditionally recommended several sessions towards the very end of life [12].

Mr. A was introduced to the idea of Dignity Therapy which resonated with him and he was interested to participate in creating a Generativity Document for his family, but unfortunately, his health deteriorated so that he was not able to return to the clinic to finish it. Usually, this therapy can be done in hospital or inpatient hospice settings, but fortunately for the patient, he was able to spend his last days at home surrounded by his family. Nonetheless, Mr. A's willingness to consider and participate in this therapeutic modality suggests that this intervention may hold promise for transplant patients in similar situations.

Practically, transplant psychiatrists can also offer a lot to their patients facing existential distress. Offering and encouraging such practical interventions as taking care of finances, deciding on surrogate decision makers if not already done, code status, burial arrangements, and so on helps patients not only feel in more control of their lives but also take care of others, knowing that their loved ones will be empowered with patients having already made some important decisions. In addition, having addressed and faced "the unthinkable" to the best of their ability allows the patient to re-focus on the here and now, and enjoys present life as much as possible. For some patients it is important to decide who will inherit their favorite collections, while others decide who will take their daughter for prom dress shopping if they are no longer there. As difficult as these decisions are, this allows patients to stay in control and take care of their loved ones. Patients can be encouraged to further express their feelings at this time through any methods that best speak to them: further discussion with mental health professionals, talking with family, friends and online communities, creating or appreciating art and music, journaling, being in nature, prayer, and meditation [13].

In addition, transplant psychiatrists can encourage patients to verbalize and ask important questions of their

transplant teams, that might not have been addressed but be important (e.g., how long do I have left, how will my death might look like, how will doctors ease my pain and suffering). Not infrequently transplant psychiatrists act as a translator between the medical world and the human existential experience for transplant candidates and recipients. In the same capacity, it might be the transplant psychiatrist who recognizes the need for and suggests the involvement of the palliative care team. Historically, transplant teams have tended to be very protective of their patients and averse to involvement of the palliative care transplant patients, either before or after transplantation, are still infrequently referred to palliative care [14]. Some of the barriers to these referrals and collaboration include (1) unrealistic expectations for survival on behalf of patients, (2) unwillingness on the part of patients and their families to plan end-of-life care, (3) seemingly contradictory goals of transplant and palliative care, (4) medical teams equating palliative care with end of life, (5) patient fear of abandonment by the transplant team, and (6) lack of access to palliative care services [14]. It may fall on the transplant psychiatrist to educate both the patient and the transplant team on the importance of palliative care interventions and involvement.

Working with transplant patients' existential distress and concerns is challenging and yet it might be the most rewarding aspect of being a transplant mental health clinician where our combination of medical and mental health expertise as well as human experience can bring the necessary space and wisdom to our transplant patients to transcend their suffering into meaning.

Take Home Points

1. Transplant patients, either pre- or post-transplantation, will bring a variety of existential concerns to their mental health providers, focusing on grief of lost experiences and expectations, meaning of life, fear and thoughts of death and dying, changes in relationships and roles, individual freedom versus dependency on others, and sense of dignity. It is important for transplant clinicians to be able to create the safe space for patients to bring up and discuss these experiences and feelings, normalize, bear witness, and validate.
2. Existential interventions, which have been studied in other chronically ill populations, can be applied to transplant patients. These include existential, meaning-centered, and dignity therapies. Studies on these interventions for transplant recipients are lacking, but would be most welcome.

3. Practical interventions that transplant mental health clinicians can employ with patients with existential distress are guiding patients to yield control over decisions they can make, while also taking care of others in their life: bringing finances into order, making a will, burial arrangements, as well as leaving letters/videos/memories for loved ones, making amends, saying goodbyes, and so on, depending on an individual case. In addition, transplant mental health clinicians can provide further education about and connect the patient with the palliative care team, if not already done.

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