# 44 Social Work Interventions in End-Stage Organ Disease and Transplant Patients

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## Introduction

Social workers play an integral role in the transplantation process for patients, their families and caregivers, and the medical teams. The focus of the practice in solid organ transplant social work involves psychosocial evaluation, addressing identified areas of psychosocial vulnerability or risk factors, and working as part of a multidisciplinary team to best support patients and their families during this complex and challenging process. While the transplant social work practices and evaluation tools may vary between transplant centers and across organ groups, the Centers for Medicare and Medicaid Services (CMS) have created mandates for all transplant centers. These mandates are aimed at standardizing care, guiding best practices, ensuring equal access to care, and ultimately protecting the health and safety of solid organ transplant patients (see Table 44.1).

**Table 44.1** CMS mandates for the solid organ transplant programs [1]

| CMS regulation reference | Regulation |
|---|---|
| Regulation X092 | A social worker must be part of the solid organ transplant team. "Transplant centers must make social services available, furnished by qualified social workers to transplant patients, living donors and their families" [1] |
| Regulation X053 | A psychosocial evaluation must be conducted for potential transplant candidates. "In nearly all cases, the transplant program must conduct and document the psychosocial evaluation conducted on a prospective transplant candidate before his/her placement on the waitlist. With exception to emergency situations" [1] |
| Regulation X093 | A qualified professional is "an individual who meets licensing requirements in the state in which he or she practices; and (1) Completed a course of study with specialization in clinical practice and holds a master's degrees from a graduate school of social work accredited by the Council on Social Work Education; or (2) Worked as a social worker in a transplant center as of June 28, 2007 and has served for at least 2 years as a social worker, 1 year of which was in a transplantation program and has established a consulting relationship with a qualified social worker" [1] (e.g., Masters of Social Work (MSW), Licensed Clinical Social Worker(LCSW)) |

## Psychosocial Evaluation

Social workers are frequently among the first transplant team members to have in-depth interactions with patients. This often begins with a thorough psychosocial evaluation.

For the purpose of this chapter, we will not cover the distinct differences in the evaluation process and unique ethical considerations that occur in the psychosocial evaluation of and work with living donors (see Chap. 4). However, it is important to acknowledge this unique area of organ transplantation in social work practice.

The psychosocial evaluation includes the patient and ideally his or her identified support persons/caregivers. This process helps the multidisciplinary transplant team identify patients' strengths and protective factors that will assist the patient in navigating the complex transplant process as well as possible risk factors that can lead to negative outcomes. The detailed psychosocial evaluation aims to optimize physical, emotional, and mental well-being of patients post-transplantation [2]. Please refer to Chap. 3 for full review of the psychosocial evaluation process for potential candidates at Stanford Health Care. The identified risk factors allow transplant social workers to develop targeted interventions to minimize risks and assist patients in optimizing their transplant candidacy and post-transplant physical and emotional outcomes. As part of their intervention, social workers refer

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patients to transplant psychiatrists for further evaluation of areas of concern and/or for treatment. Any concerns identified by transplant social workers that might interfere with successful management of a transplant are brought to the attention and discussed during the multidisciplinary transplant committee meeting [3].

Pre-transplant, psychosocial updates are completed, at minimum, annually after the initial evaluation and psychosocial needs are reassessed frequently and across the continuum of transplantation. Patient's psychosocial status might change while awaiting transplant or postoperatively (e.g., caregiver plan or mental health changes), and social workers are on the frontline to identify changes and intervene, as needed, to optimize outcomes.

## Psychoeducation

A thorough assessment of patients and caregivers' health literacy is a key component of the initial psychosocial evaluation and can help the medical team to adapt education. Social workers have an obligation to ensure that patients and families have a realistic overview of the solid organ transplant process. In fact, CMS mandates that patients are informed of both medical and psychosocial risks [1]. More specifically, CMS outlines that the potential risks of depression, post-traumatic stress disorder (PTSD), generalized anxiety disorder, anxiety regarding dependence on others, and feelings of guilt should be discussed with transplant candidates [1]. It is essential for patients to understand that solid organ transplant is not a cure and that they will be trading one disease for another condition requiring a lifetime of medical treatment. Furthermore, CMS requires that discussion of psychosocial risks takes place early in the evaluation process and is repeated whenever any major change in medical or psychosocial status occurs [1].

A multidisciplinary approach to patient education in the patient's primary language through individual or group education sessions, videos, and handouts can improve patients' understanding of the complex transplant process. Incorporating psychoeducation into the initial psychosocial evaluation can also enhance patients and families' understanding of the transplant process and reinforce information that has already been reviewed or might follow this evaluation.

## Financial Preparedness

Undergoing transplantation can significantly impact financial stability. In preparing for transplant, it is essential for social workers to provide education around the significant costs of transplantation to patients and families (see Table 44.2) [4]. Both medical and nonmedical expenses are

**Table 44.2** Estimated US average 2017 billed charges per transplant

| Transplant | 30 days pre-transplant | Procurement | Hospital transplant admission | Physician during transplant admission | 180 days post-transplant discharge | Outpatient immuno-suppressants & other prescriptions | Total |
|---|---|---|---|---|---|---|---|
| Single Organ/Tissue | | | | | | | |
| Bone Marrow -Allogenic | $60,200 | $72,200 | $465,200 | $22,600 | $249,800 | $22,700 | $892,700 |
| Bone Marrow -Autologous | 61,500 | 15,300 | 226,300 | 10,700 | 81,300 | 14,500 | 409,600 |
| Cornea | NA | NA | 21,900 | 8,300 | NA | NA | 30,200 |
| Heart | 43,300 | 102,100 | 887,400 | 92,300 | 222,800 | 34,500 | 1,382,400 |
| Intestine | 28,400 | 106,100 | 669,600 | 60,000 | 260,600 | 22,600 | 1,147,300 |
| Kidney | 30,100 | 96,800 | 159,400 | 24,900 | 75,000 | 28,600 | 414,800 |
| Liver | 41,400 | 94,100 | 463,200 | 56,100 | 126,900 | 30,800 | 812,500 |
| Lung - Single | 27,900 | 106,100 | 475,000 | 49,600 | 163.200 | 39,900 | 861,700 |
| Lung - Double | 38,800 | 127,600 | 679,100 | 68,900 | 226,500 | 49,800 | 1.190.700 |
| Pancreas | 13,400 | 97,900 | 131,400 | 19,600 | 62,600 | 22,100 | 347,000 |
| Multiple Organ | | | | | | | |
| Heart-Lung | 93,100 | 155,900 | 1,731,900 | 162,800 | 373,600 | 46,700 | 2,564,000 |
| Intestine with Other Organs | 69,000 | 260,700 | 803,200 | 96,600 | 313,000 | 42,600 | 1,585,100 |
| Kidney-Heart | 136,300 | 126,700 | 1,582,100 | 163,900 | 450,200 | 71,700 | 2,530,900 |
| Kidney-Pancreas | 36,500 | 135,100 | 274,500 | 35,900 | 107,000 | 29,100 | 618,100 |
| Liver-Kidney | 77,000 | 160.100 | 648,900 | 81.700 | 216.900 | 45,100 | 1,229.700 |
| Other Multi-Organ | 85,500 | 188,400 | 1,078,900 | 122,700 | 327,500 | 52,400 | 1,855,400 |

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important to consider in financially preparing for transplant. Anticipated medical expenses include, but are not limited to, insurance deductibles, co-pays, and post-transplant medications. Nonmedical costs include, but are not limited to, pre-transplant travel; lodging and food; medical flight for transplant; pending distance from transplant center; post-transplant temporary relocation, if indicated; and loss of wages by patients and caregivers.

Social workers can support patients and families by providing education regarding fundraising. While there is a plethora of existing fundraising organizations available, a select few are transplant specific. The National Foundation for Transplants, Children's Organ Transplant Association, and Help Hope Live are all 501(c)(3) nonprofit organizations that provide one-on-one guidance to patients and families throughout the fundraising process. The above organizations will manage funds raised and patients can submit bills for direct billing or receipts for reimbursement. Funds collected with the help of these particular organizations are not taxable due to nonprofit status and will not impact patient's eligibility for or jeopardize assistance programs, such as Medicaid or Supplemental Security Income (SSI).

## Documentation and Discharge Planning

Transplant social workers are responsible for participating in and maintaining appropriate and supporting documentation on patients throughout the transplant continuum, starting with the psychosocial evaluation. In addition, it is mandated that social workers are actively involved throughout the initial hospitalization for transplantation [1]. Social workers must partner with members of the transplant multidisciplinary team to develop comprehensive safe discharge plans to optimize outcomes after patients leave the hospital.

Discharge planning for transplant is an important topic that is first discussed during the initial psychosocial evaluation, with ongoing discussions across the transplant continuum. Social workers facilitate discussions around caregiver plans, access to medications, relocation, temporary lodging arrangements, and financial preparedness in an effort to proactively plan for discharge post-transplant. At Stanford Health Care, social workers are responsible for facilitating post-transplant lodging and ensuring that there is a safe and adequate lodging plan in place.

Available temporary lodging arrangements and resources will vary across transplant centers. In fact, at Stanford Health Care post-transplantation relocation policies vary significantly even across organ groups. For example, Stanford's lung transplant team requires their patients to reside within a 45-min radius of the hospital, including time spent in traffic. In contrast, Stanford's kidney transplant team determines whether patients are medically required to relocate on a case by case basis. If available, patients are provided with psychoeducation regarding lodging benefits through their insurance. Patients are strongly encouraged to financially prepare for relocation expenses through saving and fundraising. See financial preparedness section for further details. In the event of an ongoing financial hardship, a financial screening can be completed to assess for potential subsidies.

Lastly, education plays a significant role in the discharge planning process. Patients and their caregivers are required to participate in education with various members of the multidisciplinary team. This typically includes the post-transplant nurse coordinator, registered dietician, and pharmacist. Social workers are actively involved throughout the transplant process, but take on a critical role during the final stages of discharge planning, in addition to case managers, to ensure patients and their caregivers feel confident to leave the hospital and successfully manage care on their own**.**

## Therapeutic Interventions

Adjustment to illness can vary widely across the disease spectrum and may depend on the acute versus chronic nature of the condition. De Ridder et al. defines chronic illnesses as disorders that persist for a protracted period and impact a person's ability to function [5]. Consequently, chronic illnesses can provoke significant changes in lifestyle that may negatively impact a person's overall well-being and quality of life [6].

With a multitude of potential losses in mind, it is not surprising that some individuals with chronic illness have more difficulty adjusting than others. There are unique challenges related to the uncertain and erratic nature of the disease course [7]. Loss of control frequently pervades all aspects of a chronic illness [8]. In addition, fears regarding loss of self-image, dependency, stigma of illness, abandonment, expression of anger, isolation, and death can overtake patients with chronic illness [9]. Potential responses to chronic illness include increased anxiety, depression, alienation, abandonment, emotional ambivalence, hopelessness, powerlessness, and withdrawal from relationships [7, 10, 11]. Many of these responses occur in transplant recipients. In fact, Goetzmann et al. found that 41% of transplant recipients experienced psychosocial hardship after transplant, including depression and anxiety, psychological stress, and lower quality of life [12].

Psychosocial interventions to reduce symptoms of distress with non-pharmacological approaches may facilitate improved quality of life and more adaptive coping among post-transplant recipients [13]. Transplant social workers are at the forefront of interfacing with transplant patients and are able to evaluate their emotional states and ideally intervene with non-pharmacological measures. There are a variety of psychotherapeutic techniques available (see Chap. 43 for further details). One intervention that can be easily employed or recommended by transplant social workers is mindfulness training or mindfulness-based stress reduction (MBSR). In the first randomized controlled trial of MBSR in transplant recipients, Gross et al. found that MBSR reduced symptoms of distress and improved mental health and vitality in recipients of solid organ transplant [13]. Social workers may consider exploring MBSR training and/or recommending a MBSR program to transplant recipients.

It is also important for transplant social workers to liaise with transplant and/or community psychiatrists and therapists to refer patients for further evaluation and treatment when needed. In particular, community mental health-care providers with experience and expertise in dealing with adjustment to chronic illness can provide invaluable support and therapeutic interventions for transplant patients.

## Post-Transplant Interventions

After a patient is discharged from the hospital, social workers follow patients for the life of the organ. Social workers use outpatient clinic as an opportunity to provide ongoing assessment and psychosocial support around adjustment to life post-transplant. Having a strong social work presence in clinic can help facilitate timely interventions to optimize patients' psychosocial outcomes. During the post-transplant period, it is common for social workers to assist with a variety of issues, such as medication access, motivation and adherence, mental health concerns, caregiver support, and barriers to care such as changes in insurance, transportation issues, financial strain, and support related to end of life issues.

## Peer Support and Internet Resources

It is broadly recognized that peer support is valuable to transplant patients, but the subject is underresearched [13]. Wright found that heart transplant patients enrolled in a formal mentorship program appreciated the information and support to help them cope [14]. Interestingly, Wright further found that medical topics were among the most frequently discussed topics during such meetings, indicating that although patients had received information from their medical teams, it was essential for them to process this information with their peers who had a similar experience. In a study of liver transplant patients, the support group intervention demonstrated improved physiological, psychological, and social adaptation of liver transplant recipients [15]. In a systematic literature review of volunteer-delivered peer support programs in oncology, Campbell et al. observed that several studies found wide ranging benefits of peer support, including reassurance, reduction in isolation, increased information sharing, improved coping skills, an enhanced understanding of the experience, and a sense of normalcy [16]. Social workers can promote these valuable peer connections by developing transplant-specific peer mentorship programs and support groups.

Patients may benefit from one-to-one connections with peers who have shared experiences. Augmenting patient care through support and education from a peer perspective is the primary goal of peer mentorship programs [17]. At Stanford, the Peer-to-Peer Mentor Program is another valuable resource for patients awaiting transplant. Patients are paired with peer mentors and the two connect by email, phone, or in-person, based on personal preference and geographical proximity. The transplant social workers often assist in identifying appropriate mentors and provide them with linkage to the Peer-to-Peer Mentor Program. In addition, social workers can identify transplant candidates who may benefit from a one-to-one peer connection and provide psychoeducation about the program and benefits of peer mentorship.

Many transplant centers offer traditional in-person support groups for patients and caregivers [17]. At Stanford, Health Care, solid organ transplant support groups are generally conducted on a monthly or every other month basis lasting an hour to an hour and a half. Pre- and post-transplant patients and their caregivers are invited to attend. Social workers organize and facilitate these meetings.

Many of the Stanford transplant support groups utilize a psychoeducational framework. Social workers collaborate with the transplant multidisciplinary team to coordinate psychoeducation sessions regarding each team member's area of expertise to further support patients and their caregivers across the transplant continuum. For example, pharmacists discuss strategies for managing complex post-transplant medications, psychiatry presents on psychological care in all phases of transplantation, and transplant nurse practitioners and coordinators cover what to expect in post-transplant clinic and how to stay well post-transplant. Dieticians review the importance of nutrition, and physical therapists review the importance of staying active and strong throughout transplantation. Support groups also serve as a vehicle for physicians and transplant leadership to maintain open communication and build rapport with patients and families. Physician and transplant leadership can offer organ-specific programmatic updates while also presenting a unique opportunity for patients and caregivers to openly ask questions of the physicians and the programs. Social work will liase with local donor networks to arrange having a donor family present to the group. The donor family presentation provides a unique opportunity for patients and families to hear a donor family's perspective and the powerful impact that transplantation has on both parties.

While these in-person connections are immensely valuable, they can also be inconvenient for some patients due to geographic proximity, space, time, and patient mobility [18, 19]. Furthermore, individual and group dynamics may impact a person's willingness to contribute his or her own experiences due to concerns around privacy, confidentiality, and fear of embarrassment [18, 19]. The Internet offers individuals additional opportunities to communicate with one another anytime and remain anonymous in doing so, if preferred [18]. It allows patients and caregivers the opportunity to connect with a wide array of individuals with shared health interests worldwide [20], such as organ-specific transplantation.

Transplant recipients are now able to access organ-specific social media sites to broaden their support network [18]. Grumme and Gordon described that transplant recipients found a sanctuary in an international transplant community support group online, where recipients were able to share their unique feelings and experiences post-transplant in a safe environment [18]. Transplant recipients' postings reveal a willingness to share experiences and a sense of community for members to support each other.

Online resources might also be especially useful for younger transplant patients. For example, a pilot study on an innovative Internet program *Teens Taking Charge: Managing My Transplant Online* provided teens with solid organ transplants with relevant transplant information, self-management and transition skills, as well as opportunities for peer support [21]. Initial findings found positive regard and engagement from teens, with more interventions and studies planned by the research group [21]. Social workers can recognize such opportunities for their patient populations, bringing a variety of adapted interventions to clinics.

## Caregivers

It is widely known that the availability of one or more dedicated caregivers is a fundamental aspect of a patient's post-transplant success [22–24]. Caregivers have multifaceted roles throughout the pre-, peri-, and postoperative phases of transplant. Pre-transplant, caregivers are often required to accompany patients to medical appointments, including the pre-transplant evaluation [25]. During the perioperative phase, caregivers await surgery updates, provide bedside support, and consult with providers for medical decision-making [25]. Post-transplant, caregivers participate in bedside discharge teaching, assist in managing a complex medication regimen, provide transportation and accompany patients to follow-up appointments, assist with practical needs (e.g., meal preparation, refilling prescriptions, cleaning, laundry), provide emotional support, and potentially relocate, if indicated.

While caregiver requirements vary across transplant centers and organ groups, reviewing programmatic expectations in detail with patients and identified caregivers is essential during the psychosocial evaluation. Social workers at Stanford Health Care provide psychoeducation about the program's caregiver requirements and assess identified caregivers' ability to serve in that capacity. Caregivers should not only be available but fully functional and able to assist with a myriad of tasks post-transplant. They must be well known to transplant candidates and demonstrate full commitment to patients' post-transplant recovery. In addition, caregivers must be able to drive and have access to reliable transportation to accompany patients to their outpatient visits. Furthermore, the caregivers' physical or mental health conditions should not interfere with their ability to provide care for patients post-transplant. Alcohol, tobacco, and substance use disorders are also important considerations to assess in potential caregivers as these may impact their ability to effectively serve in that capacity. Identified caregivers must be able to take leave from work and/or other household responsibilities for the time required to serve in this role. The financial implications of taking leave from work are important to consider in assessing caregivers' ability to commit to the role. While caregivers may be eligible for unpaid job protection of up to 12 weeks annually under the Family and Medical Leave Act [26], some states, albeit quite limited, offer paid family leave programs, which can help alleviate the financial burden of caring for a loved one. Social workers can assist in determining if a caregiver meets criteria for a state paid family leave program. They can also help facilitate coordination of leave forms and documentation needed to support the caregiver's efforts to take an extended leave from their job.

Caring for patients with chronic illnesses is stressful and taxing [27]. Vitaliano et al. found that caregivers reported higher levels of somatic complaints and affective distress than non-caregivers [28]. Multiple studies have indicated that distressed caregivers often report feeling resentful, depressed, anxious, overwhelmed, and exhausted [29–31]. Caregivers often prioritize patient needs before their own during the pre-, peri-, and post-transplant periods [25]. Parekh et al. found that caregivers were more susceptible to burnout and experienced higher levels of burden when their own needs were disregarded [32]. Relationships between patients and caregivers often evolve during the transplant process with changing roles and responsibilities that can strain the relationship. Ongoing assessment of caregiver support is needed to bolster such strained relationships [33]. How caregivers cope with stress has implications for their own mental and physical health and impacts their ability to effectively meet the caregiver responsibilities [25]. Mollberg et al. suggested that caregivers may impact recipients' long-term outcomes by affecting adherence to the daily post-transplant treatment regimen [34]. With this in mind, it is essential that caregivers are well supported throughout the transplant process.

Early detection of caregiver distress and adjustment challenges affords social work clinicians a critical opportunity to provide additional support and referrals to mental health services [25], as indicated. Goetzinger et al. further emphasize the importance of a secondary caregiver plan, which offers the primary caregiver relief and respite to attend to their own needs [25]. Social workers can provide psychoeducation regarding the importance of developing a secondary caregiver plan prior to listing for transplant. Social workers can further assist distressed caregivers in developing more adaptive coping mechanisms, which can promote self-efficacy, confidence, and personal control [25].

## Conclusions

In conclusion, social workers are essential members of the multidisciplinary transplantation teams. Social workers serve a critical role providing valuable assessment, psychoeducation, treatment strategies, and interventions aimed at optimizing a patient's candidacy pre-transplant and optimizing outcomes post-transplant. Although the primary focus is often directed toward the patient, supporting the caregivers during this complex process is paramount to the success and well-being of the patient/caregiver system. More research is needed on behalf and by transplant social workers regarding a variety of multimodal interventions to further advance transplant social work practice and support patients and caregivers in having a successful transplant journey.

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