INTRODUCTION

With the introduction of cyclosporin a new era in transplantation began. Improved immunosuppression was partly responsible for the exponential growth of heart transplant programs from 1984 to 1987. The first successful lung transplant was performed by the Toronto Lung Transplant Group in 1983 and, though less dramatic, there has been a steady increase in the number of lung transplant programs since that time. More importantly, the increased frequency of organ transplantation has been accompanied by improved long-term survival. At the five heart and lung transplant programs represented by the authors of this chapter we found combined 1- and 5-year survival rates for heart (n=654) transplantation to be 89% and 75%, and for lung (n=196) transplantation to be 67% and 38%, respectively.

Survival statistics alone, however, do not reflect the challenges patients undergoing transplantation must face. The enduring focus of attention for patients and families will be the 'process' they undergo, rather than the surgery itself.

Medical social work services have historically been available to patients and their families to help meet the challenges of transplantation. As a member of the transplant health-care team the social worker assists in the selection, monitoring and rehabilitation of transplant recipients. The patients and their families are assisted in their adjustment to the psychological, emotional, social, and financial impact of transplantation. For the social worker the challenge is to continue to be a liaison between the transplant team, the patient and the family, while developing greater skills in assessing and following prospective candidates.

Bright et al., Christopherson, and others have identified a fairly predictable sequence of adjustment stages for early heart and lung transplant patients which include: (a) assessment, (b) awaiting donor, (c) immediate post-surgical, (d) recovery (first infection/rejection), (e) hospital discharge, and (f) early convalescence. In this chapter some of these stages will be combined and reference will be made to the social work services provided for heart and lung transplant recipients during the selection, perioperative, and rehabilitation phases.

ASSESSMENT PHASE

Psychosocial

The psychosocial assessment is the most important contact that a social worker has with a prospective candidate and his/her family. It should include an overall picture of the patient's personality and attitudes, mental stability and level of functioning, and current social matrix. In particular, a detailed history should be obtained of current or previous substance abuse, medical non-compliance, and psychiatric problems. Support system strengths and weaknesses, patient and family attitudes about transplantation, and the motivation and potential for post-transplant rehabilitation (physical, psychological and vocational) need to be fully evaluated. For lung transplant candidates their participation in a required post-assessment pretransplant pulmonary rehabilitation program provides an excellent opportunity to observe and further evaluate their behavior. The willingness with which they accept this requirement may in itself provide insight into their character, and into their potential post-transplant behavior.

The importance of the psychosocial assessment in determining proper patient selection has been well documented. Historically, patients have been denied transplantation on the basis of a history of (a) poor medical compliance, (b) mental illness, or (c) current or recent evidence of alcoholism or drug abuse. Recently, the validity of some of the assumptions that have been made in relation to psychosocial factors and transplantation outcomes has been questioned.

Renal transplant recipients with a prior history of heroin abuse did well when compared with other recipients. Preoperative depression and psychiatric distress were found to have little predictive value in regard to mortality and morbidity after heart transplantation. Heart transplant recipients selected with liberal psychosocial criteria, and exposed to aggressive psychosocial intervention, had medical results at 1 year similar to those of patients selected with less liberal criteria.

At many centers the policy with regard to alcohol or drug abuse is to defer patients with a current, continuing problem. However, patients are accepted once they have maintained 6 months sobriety or drug-free behavior. Following this policy at the Oklahoma
Transplantation Institute, no patient has resumed alcohol or drug consumption post-transplant, although this group has been found to be significantly more likely to develop compliance or psychological problems which were associated with increased morbidity (but not mortality) after the first post-transplant year\textsuperscript{10}.

Patient non-compliance, while sometimes difficult to identify or quantify, especially pretransplant, is an important issue that must be explored. Non-compliance has been documented to be more common in younger patients (<40 years), those single or divorced (presumably lacking family support), those with a lower level of education (less than high-school diploma), and those with no career skills\textsuperscript{11}. Some believe that non-compliance may indicate depression, intellectual deficit, cognitive impairment, or ambivalence about surgery and/or survival\textsuperscript{12}, while others report that non-compliance in regard to taking medication is mainly associated with financial restrictions\textsuperscript{13}.

Any history of failing to follow medical advice should be noted. If there are social reasons for this behavior, attention and effort must be focused on identifying the underlying issues and helping the patient to develop an effective plan of corrective action. When there is a psychological or intellectual basis for this non-compliant behavior, its potential for treatment must be assessed.

The pretransplant psychosocial evaluation must also include, when applicable, an exploration of the possibility of the patient’s return to work post-transplantation, and any need for training or education. It is reasonable to expect that the majority of thoracic organ transplant recipients will be able to resume a fully functioning lifestyle. According to a 1987 UNOS (United Network for Organ Sharing) public opinion survey on heart transplantation, 72\% of respondents agreed that a patient’s ability to return to work or other regular activities was second in importance only to patient survival (with which 83\% of respondents agreed)\textsuperscript{14}. It is at this early stage that the expectations of the transplant team with regard to the patient’s return of work post-transplant should be clearly stated. The center’s policy regarding the support (or misuse) of post-transplant disability claims should be emphasized to the patient\textsuperscript{15}. Studies have shown that a clearly stated policy which expects employment (coupled with social work intervention) results in 12–15\% of patients securing new employment\textsuperscript{16,17}.

On occasion, patients and/or family members experience some degree of disbelief and even anger when informed of the diagnosis of end-stage heart or lung disease and the need for transplantation. At times this may result in a reluctance to be totally factual during the assessment, because of the underlying fear of being denied candidacy. Potential recipients who have limited thoracic organ transplantation candidates (e.g. those with cystic fibrosis) may have difficulty in anticipating or imagining any meaningful post-transplant improvement because, due to the early age of onset of the disease and prolonged length of illness, they have no prior experience and little expectation of good health.

Financial

Before admission or transfer to the transplant service the social worker coordinates an assessment of the patient’s financial history. In countries such as the USA, with a health-care system based largely on the patient’s ability to pay, finances are a major issue. Ideally, a prospective candidate will have insurance which will cover 80–100\% of medical expenses. In the absence of private or state insurance the patient may well have to rely on his or her own personal resources or local fund-raising efforts. When problems or potential problems are identified, the social worker may provide counseling services or refer the family to appropriate community resources. It is important to remember that insurance that covers pharmacy costs is as important as hospital and physician benefits because of the expensive, and long-term, post-transplant immunosuppressive regimen.

PERIOPERATIVE PHASE

The perioperative phase refers to the time from selection through early convalescence, and is characterized by contradictory emotions for the patient and family. Although patients may express relief about being accepted as a candidate, guilt and anxiety often occur once they realize that their return to health is dependent on another’s death and the bereaved family’s willingness to donate the organs. Alternatively, the patient may secretly wish for another’s death. In some cases the patient will make known his or her idea of a suitable donor. Time spent awaiting a donor produces a severe strain on even the best of relationships within the family, or among friends. The social worker should be available to provide reassurance and emotional support and, when needed, to facilitate the ventilation of feelings. Communication with patients who have undergone transplantation is encouraged, and has proven especially helpful to candidates.

The immediate post-surgical period is, if all goes well, a time of euphoria and relatively little stress which requires only minimal social work involvement. At some point most recipients will experience a real or suspected infection and/or rejection episode. It is because of this and the other side-effects of immunosuppressive medication that a patient soon realizes that he or she may have traded one set of symptoms or problems for another. This is perhaps particularly true for the lung recipient, due to the increased risk of infection and the difficulty of diagnosing rejection after lung transplantation.

In general, recovery and the preparation for hospital discharge may be a time of incongruous feelings (i.e. frustration and depression about functional limitations and ongoing weakness, etc., accompanied by excitement about leaving the hospital). At discharge a patient is expected to once again assume responsibility for his/her own physical and emotional care, which may result in conflicts with family members who have been fulfilling a ‘care-taker’ role during the patient’s period of ill-health. Early convalescence is a furthering of this process, where a variety of family conflicts are likely to develop\textsuperscript{18}. The amount of social work involvement at this time is dependent entirely upon the needs and wishes of the patient and family.

Though successful discharge may mean resolution of many of the medical factors that precipitated admission to the hospital, what lies ahead may be uncertain. As a result, discharge is often an anxious (fearful) time for both patient and family, and they may react with confusion, shock, or denial\textsuperscript{19}. Any early unrealistic expectations about transplantation and its influence on social relationships are likely to be evident at this time.