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Commentary

These two papers from the Hospital for Sick Children and Papworth Hospital give a very clear outline of their meticulous multidisciplinary team approach to the assessment of children with cystic fibrosis being considered for heart-lung transplantation. The survival of 55%, three months to three years after transplantation, is disappointing compared with the adult figures from Papworth, presented recently, of 78% at one year and 66% at 3 years (Cystic Fibrosis Research Trust Meeting, 1991). My experience at the Brompton Hospital was broadly similar to that of the Hospital for Sick Children, though more of my patients were not accepted on the programme and consequently a large percentage on the active waiting list were actually transplanted.

Whitehead and colleagues have attempted to define the indices of poor short term survival based on deaths in their cystic fibrosis clinic over a 10 year period but fail to indicate how many patients with similar prognostic features survived for more than two years. Furthermore, they do not define the features which indicate that it is too late to consider heart-lung trans-

plantation. The mean time to death of their 10 patients who died awaiting transplantation was only 3-7 months, suggesting that selection should be based not only on a maximum projected survival of two years without heart-lung transplantation but also a minimum of three months. This might avoid some of the inevitable anguish, recrimination, and guilt suffered by the families of those who die waiting.

From the combined figures from the Brompton Hospital and Hospital for Sick Children only a sixth of the referrals had truly benefited from heart-lung transplantation, half had died either before or after the procedure, and the remainder were still waiting. These are the harsh realities which paediatricians must now present to their patients with cystic fibrosis and families, but there are additional less well defined issues which must also be considered.

The psychosocial problems which occur in those families drawn into the transplantation programme are immense. For some the hope generated has a very positive effect but for many the whole procedure is a nightmare which ends in disaster. Heart-lung transplantation is not the miraculous cure imagined by many. It merely replaces lungs diseased by cystic fibrosis with a foreign heart and lungs at perpetual risk of rejection and an inevitable iatrogenic immunodeficiency. Even if the results improve substantially, there will never be enough hearts and lungs available for all but a minority of patients. Indeed if all patients with cystic fibrosis deemed suitable for heart-lung transplantation were referred to transplant centres, in addition to the vast number of patients with other heart and lung diseases, then the percentage achieving benefit would be tiny.

The spectre of heart-lung transplantation has already affected our practice in cystic fibrosis clinics, forestalling the well established use of pleuroctomy for pneumothoraces, steroids in end stage disease, and effective terminal care. Such changes must be resisted at all costs and heart-lung transplantation should not deter continuing effort to control cystic fibrosis medically.

Can the benefit from the massive investment in heart-lung transplantation for a lucky minority really offset the suffering of the majority? This issue is far from resolution and open discussion in the journals is essential to allow us all to reach an informed opinion.

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