lead to earlier transplant and therefore avoid suffering. We have good evidence that steroids are very important in a number of chronic lung diseases including cystic fibrosis but are now more hesitant about their use because of transplantation.[5] Furthermore, pleurectomy is well established as the best treatment for recurrent pneumothoraces in cystic fibrosis but would contraindicate transplant.[6]

At a time of medical rationing with very limited resources in the health service, many paediatricians may question the wisdom of heart-lung transplantation. At present only a third of referrals will benefit from transplant, of whom two thirds may be expected to be alive at least for one year after the procedure. Many will be refused transplant for good medical reasons, and others will die waiting. I believe that heart-lung transplantation must be one final option for some patients in terminal respiratory failure. However, clear guidelines on suitability should be available to all so that unnecessary referral is avoided. Only the most psychologically robust families who fulfil appropriate criteria for severity of respiratory failure and without any of the known medical contrindications to transplant should be referred. Patients and parents should be fully aware of all the facts and figures related to the procedure. Emphasis should, however, remain on prevention, early diagnosis, and effective medical treatment for the management of the vast majority of problems that might ultimately lead to respiratory failure and the need for transplantation. No family should be left in any doubt that heart-lung transplantation is the last resort and will always remain so.

I would like to thank Ms Linda Romain for typing this paper and Ms Joanna Marchant for the diagram.

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Commentary

Heart-lung transplantation is still a new therapeutic option for end stage lung disease. As with any new treatment it was only right that experience in adult patients should be established before extending it to a paediatric population.[1 2] An initial report demonstrated that the procedure was practical and at least in the short term gave similar results to those found in adults.[3]

Three papers in this current issue address three important areas of heart-lung transplantation: namely identification of suitable patients,[4] medium term outcome,[5] and the stresses involved for staff, patients, and their families.[6] The latter presents some of the problems encountered in the first three years of a heart-lung transplantation programme in a single centre. Issues are raised which underline the importance of careful assessment before acceptance onto a transplantation programme and the important point is also made that organ supply is never likely to match demand. However, some improvements in donor supply may come from increased public awareness and the active support of paediatricians and anaesthetists responsible for intensive care. Supply is also limited by the relatively short time (four hours) that organs remain viable once removed from the donor, although there is some hope that this may be extended in the future with improved preservation techniques.[7]

In addition to highlighting important concerns about heart-lung transplantation, the experience presented does seem to have been a rather negative one with many children and their families experiencing 'increased and unnecessary suffering'. Many of the problems identified could in retrospect have been avoided. They indicate a need for greater awareness of potential problems and a high level of honesty, both within transplant teams and within those clinical teams referring patients. Hopefully this is exactly what this and the other two contributions in this issue will go some way towards achieving. Despite the problems of extrapolating from the experience of a single centre to 'all the facts' many of the underlying points made should not be discounted because of the small number of patients involved and the relative short time period. We all bear a great responsibility to introduce the transplantation option or suggest referral for assessment only when there is a realistic hope of it bringing benefit. The whole aim of transplantation should be to improve the quality of life not just to extend it. It would be more honest at this relatively early stage to view it as a palliation rather than a 'cure'. Heart-lung transplantation can provide a good quality of life for an indefinite period in exchange for continuing severe symptoms and the certainty of death.

The immediate outcomes of referral are: (i) acceptance onto an immediate or active waiting list, (ii) placing on a 'holding' or provisional list (no contraindications but not yet severe enough to transplant), and (iii) non-acceptance because either the patient is too sick (preterminal) or has major physical or psychological contraindications.[3] What has not been brought out is that patients accepted onto a provisional list may experience an increase in quality of life. This is because the decision communicates two important messages to the child and family: (i) the disease is not at a stage in which death is imminent or likely to occur in the next one to two years and (ii) transplantation offers an 'insurance policy' which may be drawn on at a later date.

Certainly no family should be assessed unless heart-lung transplantation had been fully discussed at the referral centre and the problem of ignorance on the part of the family or child should not arise. Inquiries should also be made as to the family dynamics, local family support, and major medical contraindications such as advanced liver disease and previous pleurectomy in order to forestall inappropriate refer-

rals. However, even these contraindications may change as agents such as the aprotinin (Trasylol, Bayer) make previous pleurectomy less of a problem and double lung transplantation with its improved access to the pleural cavity may enable better control of bleeding points.[8]

Assessment is bound to be stressful as issues that have been difficult to discuss within the family are brought out into the open. However, this can also be beneficial as children talk openly, often for the first time, about issues that had previously been taboo. A common theme, particularly among adolescents, is that although they knew of the severity of their condition and the risk of dying, they felt unable to talk about these fears with their parents for fear of upsetting them. Many families comment on improved motivation and more honest relationships. The presence of a transplantation programme and the fact that it is possible to restore good quality of life benefits not only the admittedly small number of children with a successful medium term outcome,[3] but also the whole population of children approaching end stage cardiopulmonary disease, letting in some hope where only inevitable deterioration and death seemed possible. This may not be an unrealistic expectation as the single largest group referred for consideration in the UK are those with cystic fibrosis. This disease accounts for approximately 30–40 deaths a year in the 5–15 year age group[4] and three to four paediatric centres could transplant something approaching this number. The problems of donor supply will remain and further improvements in controlling rejection and in identifying suitable candidates need to be made. Heart-lung transplantation and all that goes with it can certainly be stressful for health care professionals, children, and their families. The whole story cannot yet be told but an honest exposition of some of the difficulties should spur on those teams already involved to improve their procedures and alert those considering this option to the potential problems.

See related papers on p 1018 and 1022.

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