# Psychosocial adjustment of adult survivors of a paediatric dialysis and transplant programme

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# Abstract

The social adjustment of 45 young adult renal patients who commenced treatment for end stage renal disease (ESRD) as children and of 48 age and sex matched controls were compared.

Renal patients were less socially mature than controls. More lived with their parents, fewer had an intimate relationship outside the family, they had fewer school qualifications, and there was more unemployment among them. The majority, however, were in employment and the level of subjective stress and support derived from most of these areas was comparable in renal patients and in controls. Having a close relationship with a member of the opposite sex was the only domain in which renal patients reported more stress than controls. Early start of illness and current health problems were associated with poorer social outcome.

A lifelong history of ESRD leads to suboptimal or delayed social functioning on conventional indicators. However this does not lead to increased overall distress in the patients about their social circumstances and quality of life does not appear to be substantially impaired.

# (Arch Dis Child 1993;68:104-10)

Medical advances in recent years have led to increasing numbers of children with chronic illness surviving to adulthood. End stage renal disease (ESRD) is one such condition, for which the advent of dialysis and transplantation has considerably improved outcome. Although life expectancy has increased, full health is not restored and attention has increasingly been drawn to the quality of life experienced by affected individuals. This is particularly important in relation to children who grow up with ESRD and who may face a whole lifetime of suboptimal health and have to adjust to the demands and restrictions imposed by the condition and its treatment.

The physical health and development of children who receive renal replacement treatment has been well documented, but far less is known about the physical maturity and wellbeing of those who survive into adulthood. In the area of psychosocial adjustment, previous work in our unit has shown that, although most children with ESRD cope adequately with the illness and its treatment, a considerable proportion have some problem in psychiatric adjustment, the nature and severity of which vary according to the severity of the illness.<sup>1</sup> In adulthood this may put them at risk of increased psychiatric and social morbidity.

A study by the European Dialysis and Transplant Association (EDTA) looked at the rehabilitation of a large group of past paediatric renal patients in their early adult years.<sup>2</sup> Few patients were married or had children and over half the patients were unemployed. These findings are difficult to interpret as the report was based on a low response rate and no distinction was made between social, cultural, and demographic variations of participating countries. Comparable results were reported in a Japanese study by Umeyama et al, who also found activities of patients on chronic dialysis to be more limited by physical incapacity than those with a successful allograft.<sup>3</sup> However, this study fails to specify the ages of patients and major geographical and cultural differences may also apply.

A high level of psychiatric and social morbidity among young adult survivors of a paediatric dialysis and transplant programme at Guy's Hospital was reported by Henning et al.4 Although two thirds of respondents were in employment, half the group said that their disease or treatment had adversely affected their social life, and one third had seen a doctor for persistent emotional or psychiatric problems during the preceding five years. The authors highlighted the incidence of psychosexual problems among patients in long term relationships as well as the low number of patients with a stable boy/girlfriend. The findings of this study are limited, however, by the possibility of sample bias and a relatively poor response rate.

In this paper we report follow up information on the social adjustment of the survivors (aged 18 years or over) of the dialysis and transplant programme at the Booth Hall Hospital paediatric nephrology unit, a regional unit catering for all children requiring renal replacement treatment in its surrounding area. The research was commenced in 1988 to mark the 20th anniversary of the start of the paediatric programme.

In contrast to previous reports the present study aimed to review, by means of standardised interviews, the social adjustment of a group of young adults representative of the population of an entire geographical area and it makes use of age, sex, and area matched controls. It cannot be assumed that people who are delayed or atypical socially necessarily experience more suffering and as quality of life is assessed as much in terms of objective as in subjective measures, we decided to look separately at *objective* indicators of social functioning, such as employment, living arrangements, and marital

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Correspondence to: Mrs J M Reynolds, Child Mental Health Unit, Royal Manchester Children's Hospital, Hospital Road, Pendlebury, Manchester M27 1HA. Accepted 7 September 1992 status, and *subjective* indicators of stress and support in these areas of social life and relationships.

Finally, the study also aimed to examine links between illness and treatment variables, past and present, and current indicators of social life and relationships.

# Subjects and methods

THE PATIENT GROUP

All 50 subjects, who had commenced renal replacement treatment in the North West health region's paediatric dialysis and transplantation service between 1968 and 1988 and who had reached the age of 18 or over at the beginning of the study, were contacted by letter. A total of 108 children had entered treatment during that period but 38 subjects had not yet reached their 18th birthday and, at a time when mortality was still comparatively high, 20 had died. Forty five (90%) subjects consented to take part in the study.

### THE COMPARISON GROUP

A comparison group of healthy young adults was randomly selected from the registers of two general practices, chosen because they covered socioeconomic areas broadly representative of the region. Controls were selected by excluding anyone with current major illness, as recorded in the general practitioner's notes, and group matched for age and sex with the renal patients in a ratio of 3:2. This was to allow for the possibility of records being out of date and the age range in which we were interested being very mobile. A total of 85 letters were sent, resulting in contact with 62 healthy subjects. Of these, 48 (77%) consented to be interviewed for the study. There was no bias in age, sex, or geographical area among those who refused to take part.

# PROCEDURES AND INSTRUMENTS USED

The renal subjects were first seen for a physical review by a paediatrician (DG).<sup>5</sup> This included measures of height and weight and details of the effects of illness and treatment on appearance, as well as a symptom inquiry. The psychosocial interview was subsequently undertaken either at home or at the hospital. To ensure reliability of scoring, the two interviewers (JMR and MJSM) undertook joint training for the interview. The first five subjects were interviewed jointly but scored independently. Scores were subsequently discussed and agreement reached on points of difference that arose, before separate interviews were undertaken. Thereafter all scores and diagnostic ratings were discussed and agreed.

The interview was designed especially for the study and was semistructured. For all subjects the first part consisted of a demographic inquiry and questions about education, employment, social life, and personal relationship. To assess the subjective stresses or, conversely, support experienced by subjects in each of the areas, a modified version of the social stress and support inventory was used.<sup>6</sup> This provides quantifiable information and has acceptable reliability and validity. It has been found useful to study varying stresses and supports in these areas in parents of children at different stages in ESRD treatment.<sup>7</sup> Adult patients were asked additional questions about their experiences of illness and treatment and its effects on various areas of their lives. We inquired about coping strategies by showing patients five cards, each bearing a statement of strategies which have been found to help young people with chronic disorders.<sup>8</sup>

The second part of the interview for all subjects was a standardised form of psychiatric interview and subjects completed questionnaires on self esteem and parental bonding. Detailed findings from the psychiatric interview will be the subject of a separate report (M J S Morton *et al*).

Analysis of the results was carried out using the SPSS-PC program. In the first stage, descriptive statistics were used for the renal and healthy groups and the significance of differences between the groups was tested using  $\chi^2$ tests, Mann-Whitney U tests, and t tests as appropriate. The second stage comprised a closer examination of the findings from the renal group, with emphasis on illness variables associated with the main psychosocial outcome variables.

# Results

PHYSICAL CHARACTERISTICS OF RENAL PATIENTS At the time of interview 36 (80%) patients had a functioning transplant and all except one had received at least one graft during their lifetime. Two patients (4%) were currently on continuous ambulatory peritoneal dialysis and seven (16%) were on haemodialysis, although all except four patients had some experience of haemodialysis. There was wide variation in the duration of current treatment (mean 6.7 years; range 6 months-16 years) particularly in relation to graft survival. The mean age for onset of symptoms of renal disease was 8.8 years and two thirds of all patients were ill by the age of 11. Nearly all patients had commenced renal replacement treatment during adolescence, at a mean age of 14.4 years, and had been undergoing treatment for a mean (SD) of 10 (3.3) years (range 2–17 years).

Current associated physical problems at the time of the study included well recognised secondary effects of renal disease and treatment, including short stature with 32% patients being two or more standard deviations below expected height. Other problems relating to appearance were common, nearly one half had some cushingoid features and scarring was present in over 60% of patients. Half of the group had undergone frequent, repeated surgery, including three or more access operations.

# DEMOGRAPHIC

There was no major difference between the renal and comparison subjects in terms of age and sex (table 1). We did not control for social class in order to assess the effects of chronic illness or treatment in this area, but we found little variation in the social class distribution of the head of household in which subjects were living. We had information on social class distribution of family of origin for 33 renal subjects and 37 controls. This was comparable in both groups and it was also in line with social class distribution in the region.<sup>9</sup> However a significant difference in social class distribution of subjects themselves was found, with markedly fewer renal patients in social classes 1 or 2 and more ranking as unemployed.

There was no significant difference in marital status between the groups, although there was a trend for more renal patients to be single and significantly fewer had children (9% v 29%;  $\chi^2=4.8$ , 1 df; p<0.03). There were sex differences, and 46% of female renal patients were married but none of the male patients ( $\chi^2=10.3$ , 1 df; p<0.002), although two were living with partners and one had fathered a child. This compared strikingly with the healthy group in which equal numbers of males and females were married.

# EDUCATION

Nearly two thirds of renal patients had left school with some qualification but their achievements were significantly lower than those of the healthy subjects, both in terms of the number and level of examination successes achieved (table 2). The majority (71%) of patients felt that their schooling had been markedly affected by illness or treatment, often leading to difficulties keeping up with work or maintaining

Table 1 Subjects and demographic details. Results are number (%) except for sex and age

| Renal<br>patients<br>(n=45) | Healthy<br>controls<br>(n=48)  |
|-----------------------------|--|
| 21/24                       | 25/23  |
| 24.8 (18-35)                | 24.7 (17–35)   |
| 34 (76)                     | 31 (65)  |
| 9 (20)                      | 15 ( <u>31</u> )   |
| 2 (4)                       | 2 (4)  |
|                             |  |
| 7 (16)                      | 16 (33)**  |
| 10 (22)                     | 5 (10)   |
| 13 (29)                     | 18 (37)  |
| 14 (31)                     | 6 (12)   |
| 1 (2)                       | 3 (6)  |
|                             | Renal<br>patients<br>(n=45)<br>21/24<br>24.8 (18-35)<br>34 (76)<br>9 (20)<br>2 (4)<br>7 (16)<br>10 (22)<br>13 (29)<br>14 (31)<br>1 (2) |

 $^{**}\chi^2 = 10.1, 4 \text{ df}; p < 0.04.$ 

Table 2 Educational, employment, and social data. Results are number (%)

|                                | Renal<br>patients<br>(n=45) | Healthy<br>controls<br>(n=48) |
|--------------------------------|-----------------------------|-------------------------------|
| School leaving qualifications: |                             |                               |
| None                           | 16 (35)                     | 5 (10)*                       |
| CSE/'O' level                  | 26 (55)                     | 24 (50)                       |
| 'A' level                      | 3 (6)                       | 19 (40)                       |
| Current employment status:     |                             |                               |
| Full time                      | 24 (53)                     | 36 (75)**                     |
| Part time                      | 6 (13)                      | 3 (6)                         |
| Unemployed                     | 7 (16)                      | 5 (10)                        |
| Sick (disabled)                | 7 (16)                      | `                             |
| Housewife                      | _ `'                        | 1 (2)                         |
| Student                        | 1 (2)                       | 3 (6)                         |

 $\sqrt[4]{\chi^2=7.01}$ , 1 df; p<0.01.  $\chi^2=3.36$ , 1 df; p<0.04. friendships at school. A slightly higher proportion of renal patients went on to do some form of further education (76% v 69%), although a similar proportion of both groups (just over half) had some form of qualification.

#### EMPLOYMENT

Two thirds of the renal patients were in some kind of employment and just over half (significantly fewer than for the control group) were working full time in a wide range of jobs varying from professions to physical work such as gardening or warehouse work. Of the part time workers, two renal patients said they were restricted by their dialysis, but the remaining four were transplant patients, including two housewives with young children.

One third of the renal group were not working, of whom half were registered sick and disabled. Only 16% of the renal patients said they felt hindered by difficulties, real or perceived, to do with their renal condition, and some said they felt uncertain how best to present themselves to potential employers.

Income source reflected current employment status, with significantly more renal patients in receipt of social security benefits (42% v 15%:  $\chi^2 = 7.4$ , 1 df; p=0.006).

# FRIENDSHIPS AND SOCIAL LIFE

We inquired separately into social life and personal relationships. Subjects were asked firstly about the range and quality of friendships and about their leisure activities. Lack of friends or social isolation among the renal patients was uncommon but over twice as many as controls (22% v 8%) reported some limitation in this area. No differences emerged in terms of the level of leisure activities between the groups, with 82% of renal patients and 79% of healthy subjects reporting a range of hobbies and recreational activities.

Difficulties in relation to taking holidays or driving were reported no more frequently by renal patients than by healthy subjects.

# CLOSE PERSONAL RELATIONSHIPS

Two thirds of the patients, including all those on haemodialysis, but less than one third of the comparison group, were still living at home with their parents (table 3). Unlike many of the

Table 3 Close personal relationships. Results are number  $\binom{(\%)}{}$ 

|                             | Renal<br>patients<br>(n=45) | Healthy<br>controls<br>(n=48) |
|-----------------------------|-----------------------------|-------------------------------|
| Living with parents         | 31 (68)                     | 14 (29)*                      |
| Close personal relationship |                             |                               |
| with opposite sex           |                             |                               |
| Current experience:         |                             |                               |
| None                        | 23 (51)                     | 13 (27)                       |
| Some                        | 9 (20)                      | 12 (25)                       |
| Married/cohabiting          | 13 (29)                     | 23 (48)                       |
| Lifetime experience:        |                             |                               |
| None                        | 15 (34)                     | 4 (8)**                       |
| Some                        | 30 (66)                     | 44 (92)                       |

 $\frac{}{\chi^2 = 11.64, 1 \text{ df; } p < 0.001.}{\chi^2 = 6.01, 1 \text{ df; } p < 0.02.}$ 

healthy subjects, no renal patients were living with friends, for example in shared flats or other accommodation, and significantly fewer had had experience of a close relationship with a member of the opposite sex.

Twice as many healthy subjects as renal patients were married or cohabiting (48% v 24%), although there was no difference in the mean duration of the partnership (3.4 years).

## SOCIAL STRESS AND SUPPORT (FIGS 1 AND 2)

We investigated the subjective stress and support felt by the subjects at the time of assessment on these various areas of psychosocial functioning by comparing the two groups on scores from the social stress and support inventory.

Few differences of note were reported in rates for stress and support between the groups. Even though more renal patients were unemployed, there were no significant differences in the subjective stress, or conversely, in the satisfaction reported by either group in relation to occupational or financial status. There was, in fact, a trend towards lower stress among the renal patients.

In line with the few differences in social life and leisure activities between the groups, low



Figure 1 Areas of social stress measured on the social stress and support inventory showing the percentage reporting high stress; \*Mann-Whitney test p<0.05.



Figure 2 Areas of social support measured on the social stress and support inventory showing the percentage report high support.

rates of stress and high levels of support were reported in this area by both groups.

Renal patients reported closer continuing contact with their parents than healthy subjects, but they experienced only slightly more stress in the relationship, often related to aspects of illness such as the level of parental anxiety about their condition.

The area where renal patients reported significantly increased stress levels was for marriage and cohabitation. This contrasted with single patients who did not experience their single status as a stress any more than controls. Sexual difficulties were probably a contributory factor to the marital stress reported by married/ cohabiting patients as nearly a third (but less than 10% of controls) felt highly stressed regarding the physical aspects of their relationship; this was sometimes related to tiredness or feeling unwell.

Our results suggest that renal patients were less prepared for the physical demands of marriage than controls. Thus fewer patients than controls rated the physical aspect of their relationship with their partners as of great importance within the marriage (15% v 50%). In line with this, significantly fewer subjects in the total renal group reported having experienced a full sexual relationship (50% v 92%;  $\chi^2=9.5$ ; 1 df; p=0.002).

About half (as against a quarter of the controls) of all renal patients said that they had or would have welcomed some counselling or advice about sexual matters or relationships (20% of renal patients and 10% of healthy subjects had had such advice). Issues such as contraception, fertility, and pregnancy were reported by renal patients as particular areas where they would have liked more information. Several patients said they were reticent to seek advice and would have preferred doctors to initiate discussion. One young woman said she had had to summon up courage to ask her doctor if she could have children.

We inquired about the physical and mental health of spouses and about problems in children's health, behaviour, or schooling but found few problems in any of these areas among either group.

#### COPING

Patients were shown cards on which five strategies were described and asked how useful they found each strategy in coping with their illness. They were then asked to rate which one or two they found the most helpful overall.

Having a full understanding of illness and being involved in medical decisions was rated as important by over two thirds (69%) and as the most helpful strategy overall by 36% of patients. Being involved in decisions and being active in leisure activities were also important to many (60%), while under half the group rated being open and talking about illness (42%), or putting energy into work (40%), as useful methods of coping.

#### PHYSICAL ILLNESS AND TREATMENT

health and symptoms and about their experiences of treatment. The majority of patients (87%) said that they had no, or minimal, problems in their general health at that time. Minor problems included high blood pressure, anaemia, and headaches in several patients. Six patients were experiencing symptoms severe enough to cause some problems in daily life including dizziness, recurring hot flushes that prevented one young woman going out socially, and multiple problems, including depression in one haemodialysis patient who had recently been very ill. Few patients reported any difficulties of note in relation to taking medication (4%), diet (8%), fluid control (13%), dialysis, or the transplant (9%).

When asked an open ended question about problems with their physical appearance, seven (15%) said that they had a lot of problems currently in this area, but this compared favourably with the rate for problems experienced in the past (47%). When discussing current problems, patients described difficulties such as scarring or cushingoid features, but only rarely made direct reference to short stature. Significantly more past problems with physical appearance were reported by patients with current functioning transplants (67%), in contrast with those on dialysis (22%) ( $\chi^2 = 8.8$ , 2 df; p < 0.02). This often reflected an awareness of difficulties in the period after transplant, including cushingoid features, hirsutism, and other effects of medication, which had usually resolved over time.

We explored the relationship between physical illness factors and social functioning in the renal group by the use of  $\chi^2$  tests and found remarkably little association between illness variables and social outcome. On the social side we looked at marital status, living arrangements, educational qualifications, occupational status, friendships, and close personal relationships. In terms of physical factors we examined those indicative of current problems (height under 2 SDs, low energy level, subjective report of health problems, appearance, and treatment status) and of past problems (age of onset of disease and start of renal replacement treatment, history of problems in treatment, including repeated surgery).

The following significant associations emerged:

(a) Unemployment was linked to early onset of illness (before 11 years of age; p<0.005) and to low energy levels (p<0.04).

(b) Lack of a lifetime close relationship was associated with current problems in general health (p<0.04).

(c) Limitations in social contacts and friendships were more common in patients on dialysis (p<0.03).

(d) A non-significant trend emerged for patients who were still living with their parents to have had an early onset of illness (before 11 years of age; p<0.07).

There was no association between social factors and current height or appearance, age at start of renal replacement treatment, or history of recurrent problems in treatment.

#### Discussion

The results from this controlled study confirm earlier findings of delayed social development in young adult survivors with ESRD.<sup>2-4</sup> Our use of measurements of subjective stress also show that, despite their apparent poorer performance on conventional indicators of social adjustment, such as being unemployed, single, or living at home, patients' subjective adjustment in terms of the stress and support derived from various psychosocial areas was comparable with that of controls. This suggests that they were not suffering unduly from their lifestyle and that taken globally quality of life was not substantially affected by illness. Indeed, there was a trend for patients who were more age appropriate in some areas, for example that of intimate relationships, to derive an increased sense of stress in these areas, suggesting that the delays identified may be adaptive for some patients. This is further supported by our finding that the overall psychiatric adjustment of renal patients was comparable with that of controls (M J S Morton, unpublished).

This may be because during childhood, patients develop different expectations with regard to social and personal life from their age peers. Alternatively, experience of chronic childhood illness may help them develop some fortitude for dealing with adult life. Finally, this may simply indicate that delayed social development is beneficial for the wellbeing of patients with chronic illness originating in childhood.

In terms of educational performance our patients had entered adult life with some disadvantage in that fewer had school qualifications. This was not due to premature school leaving as more patients than controls had gone onto further education. It was more likely to be due to poor school performance over the years. Patients' own comments would support this view. Over two thirds felt that their schooling had been affected by illness or treatment and the difficulties in keeping up with the work. Clearly the results draw attention to the need for paediatric clinics to be alert to ways of optimising children's educational achievement.

Despite lower educational performance, the majority of renal patients were employed either full or part time, a rate comparable with that of the British study at Guy's Hospital by Henning et al,<sup>4</sup> and higher than in the European EDTA study.<sup>2</sup> However, there was more unemployment among patients in our sample than among controls. Unlike the German study by Offner et al,<sup>10</sup> unemployment was not associated with dialysis treatment but linked to illness variables, such as low energy levels and early onset of illness. It may therefore become an increasing problem as more young children enter dialysis/ transplant programmes. As for educational achievement, this is an issue requiring attention as part of the long term treatment of these children.

The lack of increased work and income related stress in patients is interesting. It is in contrast with the high number of controls who felt markedly stressed about their occupation. This may be explained by the fact that these young people were at early stages in their working lives and still adjusting to them. The findings of lower stress in the renal group may be interpreted as patients not stretching themselves enough in this area. As most of the renal patients were currently in employment, this may also suggest that they were working in supportive environments or had set themselves realistic expectations in relation to job opportunities.

Renal patients were comparable with the healthy controls in their objective and subjective adjustment in terms of social contacts and activities. In several cases they seemed to be cramming a lot into their lives, either because they were 'making up for lost time' or because they felt uncertain about their future. Social life tended to be compromised by being on dialysis but some patients seemed particularly resourceful in the way that they had successfully adapted their social or work life to the restrictions imposed by treatment or symptoms. A 27 year old woman was involved with her boyfriend in the craft business and adapted her haemodialysis sessions to fit in with craft fairs. One unemployed young man of 24 on peritoneal dialysis liked to spend a lot of time fishing and although he lacked the strength to carry his tackle, had come to rely on his friends to do this for him.

The majority of renal patients were still living with their parents (a rate comparable with that found in the Guy's and EDTA studies) and this was in sharp contrast with controls. There was thus a prolongation of renal patients' dependent status (more marked in males than in females), with fewer having started their own families. The prolongation of the dependent state appeared to lead only slightly to strain in the relationship with parents, who were regarded universally as a source of support. It is plausible to suggest that this parental support, both practical and emotional, offers protection and that a level of continuing dependency is not necessarily an indication of poor adjustment.

It was in the area of close intimate relationships that increased stress was reported by the renal group. Here again a delay is indicated in terms of objective indicators, with fewer renal patients being married or cohabiting. For those patients involved in close relationships, increased performance in objective terms in this area seems to have been achieved at a cost of increased subjective stress. Particular problems were identified in the sexual aspect of the relationship.

Henning *et al* suggested that delays in forming close relationships among renal patients were likely to be related to problems with body image such as short stature and changes in physical appearance.<sup>4</sup> Our results did not confirm this view and instead we found links between lack of experience of close relationships and problems in physical health status at the time of the study, such as low energy, dizziness, aches and pains. Sexual difficulties were ascribed by patients to physical symptomatology (that is, being tired and feeling unwell). Perhaps because of this, fewer patients than controls regarded the sexual aspects of great importance to them. Illness thus seems to have an important influence on sexual performance and interest in renal patients, and the latter may contribute to the finding of fewer intimate relationships in this group and to the stresses associated with the development of these in renal patients. Staff in clinics need to be vigilant to these issues and be in a position to assist young patients in adjusting to realistic aims and aspirations in the light of their current physical state.

Low energy levels were the reason given by patients for some of their social dysfunction, for example as it related to unemployment and problems in sexual relationships. It is difficult to know to what extent low energy was a result of poorer health status or whether it reflected a despondent and discouraged attitude by the patients about their problems or lives. Our results suggest that exploring the meaning of this symptom for individual patients at the renal clinic could help to promote social adjustment.

Problems with growth and appearance did not emerge as of great significance in our study despite emphasis given to it in the literature, for most were based on anecdotal accounts.<sup>11-13</sup> We did not specifically ask patients about their height but had anticipated that it would emerge as part of the reported concerns about appearance.

It is possible that patients felt particularly sensitive to this and 'blocked' this area for discussion, but it is also possible that short stature is only one, and perhaps a comparatively less important component, of any subjective concern about appearance. Poznanski et al support this interpretation, as they found young transplant patients who were taking high doses of steroids to be more concerned about their facial appearance and weight than about their height.<sup>14</sup> În our study, problems in physical appearance were reported most commonly in the past by patients with current functioning transplants, more so than by patients on dialysis. These reported difficulties were often dated back to the period before transplant and related to side effects of medication which had usually resolved over time.

In contrast, short stature is a chronic difficulty where concerns would diminish over time and patients would learn to adapt to their appearance as they matured. This issue continues to merit attention, particularly as growth is more often a problem with the increasing number of children entering renal treatment programmes in the current paediatric population of children with end stage renal failure.<sup>15</sup>

Our study highlights the importance placed by patients on understanding their illness and being informed of medical decisions, particularly in relation to their experience as adults, although this was also highlighted in questions about transfer from paediatric to adult units. Most patients felt that there was no optimum age for transfer but expressed, often quite forthrightly, the need to involve them directly at an early stage in adolescence about planning of the transfer as well as other medical issues.

# CONCLUSION

Our study shows an overall good level of social

adjustment in young adult survivors of end stage chronic renal failure. It highlights the importance of separating objective and subjective measures in assessing quality of life in patients. Most studies have simply looked at the former and emphasised the delayed social development. Our use of subjective indicators shows that those delays may have an adaptive value for individuals concerned. We have identified intimate and sexual relationships as areas likely to benefit from counselling for patients at the clinic. We have shown that those patients with an early start of illness and on dialysis as adults show more social delays. Special attention needs to be given on how to promote optimal coping in these patients, particularly as treatment for ESRD is starting increasingly early in childhood, with the possibility that this will lead to more problems in psychosocial delays in the future.

We would like to thank the young adults who took part in this study and also their physicians, surgeons, and general practi-tioners. We are grateful to Dr V Hillier, department of medical statistics, Manchester University, for her advice.

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# Amniocentesis and the fetal lung

Does amniocentesis cause pulmonary hypoplasia? Large epidemiological studies published in the seventies and eighties apparently suggested that neonatal respiratory problems were more common after mid-trimester amniocentesis and animal studies have shown poor lung growth. A recent report from Nottingham (A D Milner and colleagues, European Journal of Pediatrics 1992;151:458-60) gives information about neonatal lung function after mid-trimester amniocentesis.

Studies were performed on 39 healthy, full term babies born after mid-trimester amniocentesis and 42 normal control babies when the babies were between 12 hours and 8 days old. As might be expected the mothers in the amniocentesis group were significantly older (mean 34 years) than the control mothers (25 years) but otherwise the groups were similar. Using total body plethysmography and intraoesophageal pressure monitoring measurements were obtained of crying vital capacity (CVC), thoracic gas volume (TGV), dynamic compliance (DC), and total pulmonary resistance at the mid-volume point (TPR<sub>50</sub>). No significant differences between the groups were found as regards CVC, TGV, or TGV per kg body weight. There was, however, a significant reduction in DC in the amniocentesis group (p < 0.05)and a trend towards increase in  $TRP_{50}$  (p=0.1). The authors conclude that their data support the hypothesis that mid-trimester amniocentesis may affect lung growth in the fetus. It would be nice to know whether increasing maternal age itself has any effect on neonatal lung function. The clinical significance of the findings seems uncertain.

In the same issue of the European Journal of Pediatrics workers from King's College Hospital, London (P Thompson and colleagues, 1992;151:455-7) report their studies of babies born after prolonged (more than a week) preterm rupture of the membranes. Using a helium gas dilution technique they measured functional residual capacity in 22 such babies at ages up to 2 years and in 50 healthy controls and they found no changes attributable to the prolonged rupture of the membranes.