# Quality of life following liver transplantation: a preliminary report

DEREK LOWE, MSc, MIS, Lecturer in Medical Statistics JOHN G. O'GRADY, MD, MRCPI, Senior Lecturer in Medicine JAMES MCEWEN, FFCM, MFOM, Director, Department of Community Medicine ROGER WILLIAMS, MD, FRCP, FRCS, Director, Liver Unit King's College School of Medicine and Dentistry, London

ABSTRACT – Although the quality of life attained after heart transplantation has been assessed, there is no equivalent information for recipients of liver grafts in this country. In this paper we report a cross-sectional survey of 81 adult patients in the Cambridge/King's College Hospital joint programme using the Nottingham Health Profile which is a validated measurement of the quality of life. The results show the quality of life to be high, and broadly similar to the levels expected in the general population. The data suggest an increase in the problems related to physical mobility (two-fold) and a reduction in problems of emotional reaction (a halving).

The standard measures for assessing medical and surgical procedures are clinical judgements, laboratory and other investigations and survival rates. However, the measurement of perceived health is a very useful additional yardstick of outcome. The Nottingham Health Profile [1] was chosen to assess perceived health as it has been used in the study of costs and benefits of the heart transplant programmes at Harefield and Papworth hospitals [2]. It was selected for that study as it was an existing validated instrument which was considered to be sensitive to a wide range of health states, comparative population Nottingham Health Profile scores were available, it could be administered by interview or mail, and it made relatively small demands on patients and efforts [3].

The first report of the European Liver Transplant Registry outlined the encouraging survival figures [4] but made no assessment of the subsequent quality of life. The Pittsburgh group administered a large battery of neuropsychological tests, including the general health questionnaire and sickness impact profile, to a selected group of patients admitted to their liver transplant programme, and in an early prospective analysis Tarter *et al.* suggested an across-the-board improvement following transplantation [5]. The present paper describes the results of a cross-sectional survey to measure the quality of life in patients being treated in the Cambridge/King's College Hospital programme in March 1987.

### Materials and methods

The Nottingham Health Profile is a simple self-completion questionnaire in two parts, which does not require any special instruction or equipment. Part I contains 38 statements covering feelings and functions in six areas: pain, energy, physical mobility, sleep, social isolation and emotional reactions. The respondent is invited to indicate 'yes' or 'no' (thus forcing a definite choice) according to whether or not the statement applies to him or her 'in general'. There are no negative statements in the profile. These statements vary in severity and this is reflected in the empirical score attributed to each one. The maximum overall score is 100, with such a score indicating extensive problems in all areas assessed. Part II contains 7 statements examining the impact of health on occupation, ability to perform domestic tasks, personal relationships, sex life, social life, hobbies and holidays. Each statement scores 1 for a 'yes' and 0 for a 'no' reply. Age and sex norms have been determined previously for both parts I and II in a community sample drawn from a general practice population [2].

During March 1987 the questionnaire was mailed to all 81 liver transplant recipients who were alive and discharged from hospital. This cohort represents 40% of 205 consecutive adults who had received transplants between December 1976 and January 1987, while the 40 patients treated in the last 13 months of this period accounted for two-thirds of all the transplants carried out during this time.

Additional data collected were the date of transplantation, place of residence and a clinical assessment of graft function and other significant medical problems at the time of circulating the questionnaire. Liver function was categorised as good (normal blood tests), fair (no related symptoms but with some abnormal blood tests) or poor (symptomatic and abnormal tests). Other medical problems, which included conditions possibly related to the original liver disease, eg osteoporosis, were categorised as absent, minor (asymptomatic but possibly needing medication),

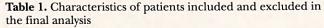
Address for correspondence: Mr Derek Lowe, Department of Community Medicine, King's College School of Medicine and Dentistry, Bessemer Road, London SE5 9PJ.

moderate (likely to cause symptoms but not thought to interfere with lifestyle) or severe (interfering with lifestyle or likely to cause premature death). The data were analysed for three time periods since transplantation: less than 1 year, 1–2 years and more than 2 years. Recognising the difficulties in using the NHP in different cultures, residence was coded as either living in the UK and the Republic of Ireland or in other areas.

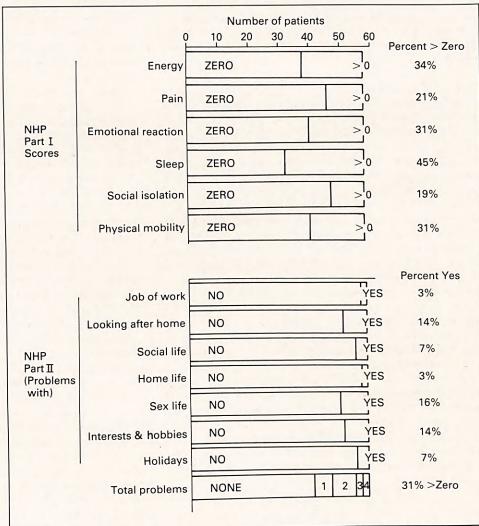
#### Results

A total of 64 (79%) of the 81 questionnaires were returned; the non-response rate was higher in those living abroad (Italy 2, Spain 2, Portugal, Sweden, Germany, France, Yugoslavia, Israel, Yemen, Australia) and in those with moderate/severe medical problems—1 severe (malignancy), 3 moderate (malignancy), 6 minor (osteoporosis, myeloproliferative disorder, nephrotic syndrome, hypertension, inferior vena cava obstruction). Six respondents were excluded because of incomplete data, leaving 58 patients for analysis. The patient characteristics of the 58 analysed and the 23 exclusions or non-responders are summarised in Table 1. The 58 patients analysed had a mean age of

Fig. 1. Nottingham Health Profile results indicating the proportion of patients reporting problems in the areas assessed in Parts I and II of the questionnaire.



			ncluded $(N=58)$	Excluded $(N=23)$
Age (years)	<30		10	7
	30-39		17	5
	40-49		18	
	>49		13	4 7
Men/women			24/34	10/13
Time from transplant		<1	25	11
(years)	1	1-2	13	8
., ,		>2	20	4
Liver function		Good	54	19
		Fair/poor	4	4
Other medical		Yes	15	10
conditions		No	43	13
Residence		Abroad	11	12
		UK/Irelan	d 47	11



**Fig. 2.** Comparison of mean scores for Part I in liver transplant patients (N = 58) and age/sex controlled community population.

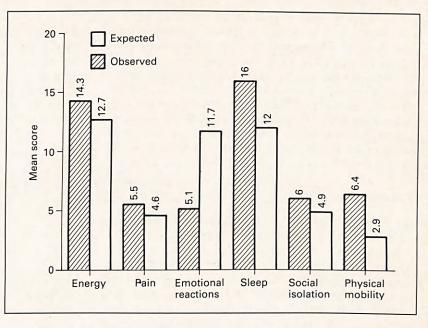
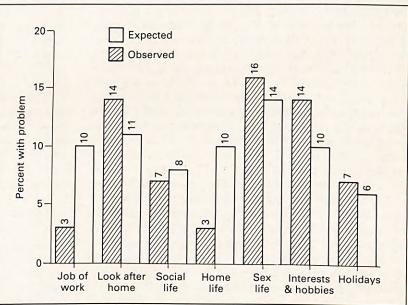


Fig. 3. Comparison of Part II responses for liver transplant patients (N = 58) and age/sex controlled community population.



42 years (range 21-66 years); 24 (41%) were men and 10 (17%) were resident abroad (Italy 3, Israel 2, Greece, Portugal, Sweden, Pakistan, Australia, New Zealand). All but four were classified as having good graft function (3 fair, 1 poor). Fifteen patients were noted to have other medical problems: 3 severe (malignancy), 3 moderate (osteoporosis, renal impairment, diabetes mellitus), 9 minor (myeloproliferative disorder, hypertension, oesophageal stricture, hepatitis B, obesity, cardiac disease). Twenty-five patients (43%) were within 1 year of transplantation, while 13 (22%) and 20 (34%) were at 1-2 and more than 2 years respectively.

Twenty-seven patients (47%) scored zero for all six areas profiled in Part I of the questionnaire, indicating that almost half were free of all such problems (Fig. 1).

The commonest problem reported concerned sleep (45%) and the least frequent was social isolation (19%). The mean scores for each of the six areas were compared to levels expected for community-based age/sex norms (Fig. 2). This indicates an excess of problems in physical mobility (twofold increase) but a halving in problems of emotional reaction in the transplant group, with the other scores approximating to the expected levels. Amongst patients resident in the UK or the Republic of Ireland and free of medical problems, difficulties with emotional reactions were reported at less than one-third of the expected level. Patients within one year of transplantation reported greater problems with physical mobility, energy and social isolation than their counterparts who had the transplant some time earlier.

Two-thirds of the patients reported that they were free of all seven problems in Part II of the questionnaire (Fig. 1) The mean number of problems for the transplant group was 0.6, compared with 0.7 in the age/sex norms. Transplant patients reported fewer problems in the home life and job of work sections, while the level of problems encountered in other activities was similar to that expected (Fig. 3). Amongst the patients resident in the UK or the Republic of Ireland who had no medical problems, the level of reported problems was half that expected in age/sex norms.

#### Discussion

The results of this cross-sectional study show that patients who have had a successful liver transplant report a very high quality of life-broadly similar to that for the same age and sex in the general population. Considering that the main criterion for selection for transplantation is the presence of end-stage liver disease for which all other available therapies have been tried, this represents a remarkable improvement over the quality of life 'enjoyed' prior to transplantation. Indeed, many of the patients spontaneously wrote that the health profile questionnaire gave no opportunity to comment on the very positive feelings of well-being that they were experiencing. Although the Nottingham Health Profile is a relatively severe instrument, and when used in the 'healthy population' the questionnaire is rather negative, this level of spontaneous comment has not previously been encountered in general population surveys. It reflects the dramatic improvement in perceived health of the liver transplant patients.

These results are in general agreement with those reported following heart transplantation. Observed and expected scores derived from Table 9.5 of DHSS report No. 12 [1] for men 3 months after transplantation indicate a fivefold excess for problems with physical mobility (observed mean 11.0, expected mean 2.3) and close to a halving for difficulties with emotional reactions (observed mean 5.5, expected mean 9.2). The remaining areas are in close agreement. For issues covered by Part II, the fewest problems for cardiac transplant patients after 3 months were homelife (2%) and looking after the home (10%), compared with 3% and 14% respectively in the liver recipients.

Some factors that might influence perceived health after transplantation are symptoms from a pre-existing complication of liver disease (eg osteoporosis in primary biliary cirrhosis) which could affect physical mobility, or residual damage from a previous severe illness. On the other hand, post-transplant euphoria, an overraction to regained health, and a desire to demonstrate gratitude could positively influence the levels of reported health status. Variations between the transplant and general populations in their socio-economic structure could lessen the relevance of age/sex community norms, but there is no evidence that this is a major factor in the current study. Having shown that the quality of life as reflected by the Nottingham Health Profile is high following liver transplantation, the next step will be to examine prospectively the outcome in different categories of patient. This may assist not only with the selection of patients for surgery, but also in planning the likely need for rehabilitation, psychosocial support and other services following liver transplantation.

### Acknowledgements

The liver transplants in this study were carried out under the direction of Professor Sir Roy Calne, Department of Surgery, Addenbrooke's Hospital, Cambridge.

#### References

- 1. Hunt, S. M., McEwen, J. and McKenna, S. P. (1986) Measuring health status, pp 163-202. London: Croom Helm.
- Buxton, M., Acheson, R., Caine, N. et al. (1985) Costs and benefits of the heart transplant programmes at Harefield and Papworth hospitals, pp 91–106. London: HMSO.
- O'Brien, B. J., Buxton, M. J. and Ferguson, B. A. (1987) Measuring the effectiveness of heart transplant programmes: quality of life data and their relationship to survival analysis. *Journal of Chronic Diseases*, 40, Suppl 1, 1375–1535.
- Bismuth, H., Castaing, D., Ericzon, B. G. et al. (1987) Hepatic transplantation in Europe. Lancet, ii, 674–6.
- Tarter, R. E., Erb, S., Biller, P. A. et al. (1988) The quality of life following liver transplantation: a preliminary report. Gastroenterology Clinics of North America, 17, 207–17.

## Royal College of Physicians of London DIPLOMA IN GERIATRIC MEDICINE

The Diploma in Geriatric Medicine is designed to give recognition of competence in the provision of care for the elderly and is particularly suitable for General Practitioner vocational trainees, Clinical Assistants and other doctors working in non-consultant career posts in Departments of Geriatric Medicine, and other doctors with interests in or who have responsibilities for the care of the elderly.

The next examination will begin on Tuesday, 10th April 1990. Application forms, together with the necessary documentation, must reach the College by Friday, 2nd March 1990.

Candidates must either have held a post approved for professional training in a department specialising in the care of the elderly, or have had experience over a period of 2 years since Full Registration or equivalent in which the care of the elderly formed a significant part.

Further details and an application form may be obtained from:-

Examinations Office, Royal College of Physicians of London, 11 St Andrew's Place, Regent's Park, London NW1 4LE.