



0959-8049(95)00643-5

## Special Paper

# Measuring the Meaning of Life for Patients with Incurable Cancer: The Life Evaluation Questionnaire (LEQ)

P. Salmon,<sup>1</sup> F. Manzi<sup>2</sup> and R.M. Valori<sup>3</sup>

<sup>1</sup>Department of Clinical Psychology, Whelan Building, University of Liverpool, P.O. Box 147, Liverpool L69 3BX; <sup>2</sup>Middlesex Hospital, London; and <sup>3</sup>Gastrointestinal Unit, Gloucester Royal Hospital, Great Western Road, Gloucester, U.K.

Clinical observation, systematic research and popular anecdote indicate that, when confronted by death, people change the criteria by which they evaluate their lives. Questionnaires used routinely to assess quality of life in people with poor-prognosis cancer tend to be symptom-based and do not assess factors which become important when confronted by fatal illness, such as the meaning of life and the degree to which life has been enriched by the illness. To develop a questionnaire which would be sensitive to these areas, patients with incurable cancer and carers of such patients were interviewed in depth. Responses were reviewed by a panel of patients, clinicians and carers and formed into an inventory which was completed by 200 similar patients. Principal components analysis identified five dimensions: clearer perception of the meaning of life; freedom versus restriction of life; resentment of the illness; contentment with past and present life; past and present social integration. Only the most symptom-oriented scales (freedom, resentment) correlated with the Rotterdam Symptom Checklist. Scale scores showed that younger patients were more resentful of their illness, but also gained a clearer perception of the meaning of life. This questionnaire can evaluate psychological needs of people with incurable cancer which are neglected by existing instruments. Copyright © 1996 Elsevier Science Ltd

**Key words:** quality of life, cancer

*Eur J Cancer*, Vol. 32A, No. 5, pp. 755-760, 1996

## INTRODUCTION

RECENT CRITICISMS of the way that quality of life is routinely assessed have emphasised the danger of neglecting the patients' perspective [1-3]. That is, rather than focus on domains of experience that are the conventional concern of clinicians, assessment should reflect the criteria by which patients evaluate their lives. Questionnaires used to measure quality of life in cancer attempt this to varying degrees. One approach has been to measure symptoms. This is illustrated in widely used questionnaires, such as the Rotterdam Symptom Checklist [4]. Another has been to measure performance of everyday activities by surveying social, sexual, occupational and domestic functioning [5]. There are, however, indications that aspects of experience which are excluded from both these approaches [6] are profoundly important in patients with poor prognosis or incurable cancer [7].

Clinical observation indicates that, when confronted by

illness which is incurable and fatal, people change the criteria according to which they evaluate the quality of their lives. Examples include: the extent to which life has been enriched by the experience of illness; a closer inspection of past life and achievement; and the prospects for families left behind after death. Moreover, there is now evidence to confirm that the domains of life experience that underly life satisfaction in patients with poor prognosis cancer are different from those that matter to patients with less threatening illness or to healthy controls [8]. In addition, published accounts of adaptation to trauma, including mortal illness, have documented the search for meaning in the illness, in particular by seeing one's life as improved by the illness [9, 10]. These observations are consistent with popular anecdote [11], in which people threatened by death describe being less troubled by minor stresses and appreciating life more than before. In this way, satisfaction with life can be maintained in the face of serious illness [8].

There is a theoretical basis for these observations in accounts of life-span emotional development. These maintain

Correspondence to P. Salmon.

Received 25 Jul. 1995; revised 10 Nov. 1995; accepted 22 Nov. 1995.

that the normal challenges of adulthood—and especially the approach of death in later life—stimulate a change in values. According to Erickson, the final stage of adult psychosocial development [12, 13] revolves around a conflict between ‘integrity’ (a sense of completeness and fulfilment) and ‘despair’ (fear of death and regret at lost opportunity). In a separate theory, Levinson [14] identifies confrontation with one’s mortality as an important developmental task, from which greater fulfilment can emerge.

Clinical interventions in incurable cancer such as palliative medical treatment and counselling should, therefore, be evaluated by effects on emotional and intellectual adjustment as well as on more conventional domains. There have been previous attempts to devise scales to measure purpose or meaning in life [15–19], but these generally reflect authors’ theoretical or spiritual orientations. Only one has been designed for patients with a life-threatening illness [19], but this has very little construct or content validity.

The primary aim of the present study was to devise an inventory sensitive to aspects of life experience that are relevant to people with incurable cancer but are not measured by established inventories. A second aim was to compare scales derived from this inventory with those from an established questionnaire [4] and from one devised with similar aims to ours [20] to determine whether our technique could detect unique components such as the ‘meaning’ of illness and the evaluation of past life. A third aim was to test construct validity by examining how scores related to patients’ age. Intuitively, and according to developmental theory, younger sufferers should be more angry and resentful about their illness because they are less likely to have come to terms with the certainty of death. Correspondingly, any psychological benefits of the illness, such as increased appreciation of life, should be more prominent at a younger age.

To maximise its validity, the content of the questionnaire was based on in-depth interviews of patients and carers. These ranged more widely than conventional concerns with symptoms or function to include the ‘meaning’ of the illness. The refinement of the scale was driven by patients’ and carers’ assessments rather than by theory.

## MATERIALS AND METHODS

### *Derivation of the Life Evaluation Questionnaire (LEQ)*

13 patients to be interviewed were selected from wards of a central London teaching hospital according to the following criteria: (i) they had poor prognosis cancer (pancreatic, bile duct or oesophageal); (ii) they had been told that their cancer was incurable; (iii) they had, in the view of the principal clinician, accepted this diagnosis and prognosis; (iv) they were judged by the clinician to be capable of talking about their illness without undue distress.

All patients agreed to take part. In addition, two spouses of these patients were interviewed, as were five nurses who cared for these and other patients with incurable cancer. Interviews were conducted by a male psychologist, under supervision of a physician and clinical psychologist, and lasted between 30 and 90 min. They were semi-structured: patients were encouraged to talk freely at their own pace, but were carefully prompted to talk about their past, present and future life, both generally and with reference to specific topics including their illness, activities, achievements, regrets and social relationships.

Every comment which signified evaluation was noted.

Evaluation could be explicit (e.g. “it upsets me that friends seem to keep away from me”) or implicit (“friends don’t know how to deal with me”). Ambiguous and clearly idiosyncratic comments were discarded. References to illness-specific symptoms were excluded. Remaining comments with similar meaning were grouped and a pair of opposing statements was constructed to reflect this meaning. As far as possible these retained patients’ own words. Items were carefully written so as not to imply a presumption of serious illness or impending death. Opposing items were placed at each end of a 0–6 scale, and formed 121 items for the draft Life Evaluation Questionnaire (LEQ).

The draft questionnaire was discussed in detail and individually with a panel consisting of: (i) a patient with pancreatic cancer, aware of his poor prognosis; (ii) three consultants and two senior nurses caring for poor prognosis cancer patients; (iii) a consultant psychiatrist with experience of cancer patients; (iv) two clinical psychologists with clinical and research interest in cancer; (v) a medical researcher into quality of life in cancer; (vi) a journalist writing for a popular newspaper.

The panel was asked to comment on (i) the exhaustiveness or repetitiveness of the content of the questionnaire; (ii) the acceptability of its items; and (iii) its clarity. Finally, after an open meeting including physicians, surgeons, nurses and psychologists to review these comments, 61 items remained.

To convince colleagues and ourselves of its acceptability, 20 patients with oesophageal cancer, pancreatic cancer or cholangiocarcinoma, selected by their supervising clinicians, were asked to complete the questionnaire. The patients gave their opinion of it to the researcher and later to a separate research nurse, known to the patients, who was independent of the study.

### *Validation of the LEQ*

**Subjects.** Consecutive patients from outpatient clinics ( $n = 76$ ) and hospital wards ( $n = 125$ ) of two inner London teaching hospitals were approached according to two criteria: (i) they had incurable cancer and (ii) the supervising clinician or senior nurse confirmed that the patient had been told this unambiguously.

So as not to exclude patients who were denying their illness, patients were not selected on the basis of their own report of their diagnosis and prognosis. They were asked to take part in a survey that was being carried out ‘every week in different parts of the hospital’ into ‘how people feel about their illness and its effect on their lives’. The female researcher remained with or near them while they completed the questionnaire and prompted patients to answer unanswered questions. Medical and demographic data were obtained from the patient and from the hospital records. One inpatient declined to take part, before reading the questionnaires.

**Questionnaires.** In addition to the LEQ, patients completed the Rotterdam Symptom Checklist (RSCL [4]) and a scale reported by MacAdam and Smith [20]. After checking for extreme skewness, responses to LEQ items were subjected to principal components analysis, using the correlation matrix so as to standardise the scores. The number of components to retain for orthogonal (Varimax) rotation was chosen with the aid of a Scree test. Items loading at  $\geq 0.40$  were used to define the components. Orthogonal rotation was chosen because of the need to identify dimensions of life evaluation that are independent of one another. Component-based scale scores

were calculated for each component by summing the scores on the items loading on that component, taking account of the sign. Because of their independence, it is inappropriate to sum the scale scores to produce a total score. MacAdam and Smith's questionnaire and the RSCL were scored as described in the respective reports [4, 20]. Failure to find correlations with the LEQ might be explained by failure of the dimensional structure of their items, rather than the relevance of the items themselves, to generalise to a poor prognosis population. Therefore, scores were also calculated for scales formed from principal components analyses of the responses to each of these questionnaires, performed as above. Relationships of LEQ scores to the other questionnaires were assessed by product-moment correlations; values not reaching  $P < 0.01$  were disregarded.

**Reliability.** The first 40 inpatients recruited were asked to complete the LEQ a second time 48–72 h after the first. All complied. Test-retest reliability of component-based scale scores was assessed by product-moment correlations. Internal consistency was assessed by Cronbach's  $\alpha$ ; values  $\geq 0.70$  are conventionally considered acceptable.

**Analyses of variance.** The sample was trichotomised (at ages 50 and 65 years) and the resulting groups compared by analysis of variance of the LEQ scales and original RSCL scales. Significant effects were examined by *post hoc t*-tests using the error term from the analysis of variance. A separate analysis compared the sexes on the same scales.

## RESULTS

### Acceptability of the questionnaire

All of the 20 pilot patients completed the questionnaire, no patient was critical of it and a number commented on the opportunity that it provided to express concerns that were normally unexpressed. In the main study, no patient declined to participate once they had read the questionnaire. Again, no patient was critical of its content and many commented that they valued the opportunity to express the views that it sought.

### Sample

200 patients were recruited (116 male, 84 female). The main types of cancer were lung, myeloma, oesophageal, breast and colon (Table 1). The median number of weeks which

Table 1. Principal diagnoses of patients forming the validation sample

Cancer	n
Lung	26
Myeloma	24
Oesophageal	18
Breast	16
Colon	13
Prostate	12
Ovarian	11
Non-Hodgkin's lymphoma	11
Stomach	8
Lymphoma	7
Bladder	7
Rectal	6
Cholangiocarcinoma	5
Others	36

elapsed since diagnosis was 52 (range 2–884). 58 were employed or self-employed; 99 were retired and the remainder were unemployed or home-makers. 137 had left education before or at the age of 16 years, 41 were educated to GCSE/O level standard (i.e. academic examinations normally taken at age 16 years in the U.K.) and 29 at least to A level (normally taken at age 18 years or later); 124 described themselves as Protestant/Church of England, 33 as Catholic. Jews ( $n = 8$ ), Hindus ( $n = 2$ ) and Muslims ( $n = 1$ ) were very few. Only 14 described themselves as having no religion; 14 reported mothers that were born in Asia, Africa or the West Indies.

### Life Evaluation Questionnaire

For each item, the proportion of the sample responding at either side of the midpoint is shown in Table 2. Two items ('I can easily get in touch with a doctor or nurse when I want to/I can't ....', 'I am very happy with the way that the doctors and nurses have looked after me/.... not at all happy ....') were eliminated because of extreme skewness ( $\geq 87\%$  in two adjacent scoring bands). From the principal components analysis of the remaining items, five components, explaining 37.4% of the variance (eigenvalues: 10.21, 4.01, 3.13, 2.46), were retained for rotation. Items that failed to load concerned: pain, life after death, getting depressed, money problems, 'feeling bad about things I have done', enjoying work or housework, GP understanding, 'I should have done more with my life', feeling anxious, enjoying eating, family/friends needing 'me to help them cope', doctors' ability to help, worry about things left undone, concentration, hobbies/pastimes, prayer. The results for remaining items are shown in Table 2.

Component 1, 'Freedom versus restriction', describes the extent of freedom from restrictions imposed by illness. It contrasts the feeling that life is continuing despite illness to one that illness has arrested life. The second component, 'Appreciation of life', describes whether a patient has, or has not, gained from the illness, principally in terms of clarified perception of priorities in life including close relationships. 'Social integration' describes the level of support and intimacy experienced currently and in the past. It is not simply an index of social activity, since 'never feeling lonely' loads on a different scale: 'Contentment'. This describes satisfaction with past and present life. 'Resentment' is focused on the shortening of life by illness and the way that illness has impaired life. Internal consistency and test-retest reliability coefficients of the component-based scales were high (Table 3).

### RSCL and MacAdam and Smith questionnaires

From the principal components analysis of the RSCL, three components were extracted, explaining 37.4% of the variance. They described psychological symptoms, GI/digestive symptoms and pain symptoms. The MacAdam and Smith scale yielded six components, explaining 50.2% of the variance. They described: gloom, support, digestive symptoms, excretion, physical comfort and positive outlook.

### Convergent and divergent validation

Correlations of the LEQ scales with RSCL and MacAdam scales are shown in Table 3 and discussed below.

### Analyses of variance

There were 33 patients aged  $< 50$  years, 89 aged 50 to 65 years and 76 aged  $> 65$  years. In the analysis of LEQ scores,

Table 2. Results of principal components analysis of LEQ responses. Items loading at  $\geq 0.40$  are shown. The ratio shows numbers of patients agreeing/disagreeing with each item as stated (neglecting those scoring at the midpoint)

	Ratio	Freedom versus restriction	Appreciation of life	Contentment	Resentment	Social integration
I am able to do all the things I want to	59/114	0.66				
I sleep well	110/63	0.65				
I never feel tired	48/101	0.60				
Symptoms don't stop me doing or enjoying things	84/88	0.57				
I am keeping active	117/61	0.57				
I find it easy to relax	127/43	0.56				
I do not have symptoms that bother me	87/87	0.54				
I do not expect illness to cause pain in the future	64/97	0.51				
There is a lot I can do to make myself better	140/39	0.50				
There are many things I'm looking forward to	159/15	0.44				
I appreciate things more than I did	162/25		0.58			
My illness has helped free me from doing things	47/111		0.55			
I have a much clearer idea now what is important in life	124/45		0.54			
There are many people I feel closer to now	130/54		0.50			
Something good has come out of my illness	90/83		0.45			
I never feel lonely	154/26			0.61		
I have enjoyed life so far	170/18			0.60		
The doctors and nurses understand what I need from them	181/15			0.60		
Every day there is something I enjoy	173/12			0.60		
I can deal with the problems that face me	146/38			0.59		
I am happy with the way I was told about my illness	146/40			0.52		
My life is not disrupted by visits to the doctor	114/60			0.49		
My illness has not cut me off from people	146/43			0.44		
I worry a lot about how long or short my life will be	66/107				0.78	
I am frightened of what dying will be like	43/121				0.67	
I can't take my mind off my illness	51/123				0.63	
My illness has upset important plans	85/95				0.54	
When I get sad it stops me doing things	38/143				0.52	
Minor upsets bother me more now	37/143				0.50	
I always feel frustrated	71/99				0.47	
I am embarrassed about illness and treatment	54/132				0.47	
Symptoms bother me every day	87/87				0.47	
I always feel angry	31/138				0.46	
I am worried that I'll be a burden	100/77				0.46	
I am a great burden to people	32/149				0.44	
It feels unfair that I have this illness	91/77				0.40	
Friends know just how to deal with me	144/19					0.66
On the whole life has treated me well	172/11					0.64
There is always someone I can talk to about how I feel	181/12					0.64
My friends and family give me all the support I want	189/10					0.54
My home/family life has been rewarding	184/10					0.51
I have many close friends	161/18					0.50
I am very satisfied with the amount of information I have about my illness	175/15					0.50
I have enough people to talk to about my illness	168/20					0.43

age groups differed on Appreciation of Life ( $F(2,195) = 3.25$ ,  $P < 0.05$ ) and Resentment ( $F(2,195) = 4.23$ ,  $P < 0.05$ ). *Post hoc* tests showed that the youngest age group were more resentful of their illness than those aged 50–65 years who were, in turn, more resentful than the oldest group but both the youngest patients and those aged 50–65 years gained more from the illness in terms of appreciation of life than did the oldest patients (Table 4;  $P < 0.05$ ). The MacAdam and Smith questionnaire showed only that Fear declined with age ( $F(2,195) = 9.03$ ,  $P < 0.001$ ; Table 4); each age group differed from the next ( $P < 0.05$ ). No difference on RSCL scales approached significance. The sexes did not differ on any scale.

## DISCUSSION

The Life Evaluation Questionnaire is a highly acceptable and reliable way of measuring how patients with incurable cancer evaluate their lives. Its content indicates a sensitivity to aspects of experience which are disregarded by existing instruments. This is borne out by a highly reliable component subscale measuring the extent to which illness was seen as having enhanced life, in particular by clarifying priorities, and which was completely unrelated to assessments made using either of two existing instruments. The high proportion of patients who answered positively to the items that formed this scale further vindicates the inclusion of these questions.

Table 3. Product-moment correlations of LEQ scales with the RSCL and MacAdam and Smith questionnaires scaled conventionally and on the basis of principal components analyses of responses of the present sample

			LEQ scale				
			Freedom	Appreciation of life	Contentment	Resentment	Social integration
Reliability	$\alpha$	Test-retest	0.70	0.76	0.76	0.85	0.78
			0.80	0.91	0.77	0.92	0.84
RSCL	Original	Physical	-0.62†	-0.01	-0.18	0.43†	-0.31*
		Psychological	-0.52†	-0.11	-0.32†	0.63†	-0.31*
	Derived	Pain	-0.41†	0.04	-0.11	0.36†	-0.28*
		GI/digestive	-0.50†	-0.04	-0.15	0.33†	-0.21*
		Psychological	-0.52†	-0.12	-0.34†	0.63†	-0.34†
MacAdam and Smith	Original	Mood	-0.54†	-0.20*	-0.38†	0.42†	-0.41†
		Fear	-0.39†	0.02	0.27*	0.59†	-0.26*
		GI	-0.35†	-0.07	-0.17	0.28*	-0.21*
		Knowledge	0.21*	0.20*	0.37†	-0.17	0.39†
		Support	0.11	0.08	0.26*	0.02	0.41†
	Derived	Gloom	-0.38†	0.06	-0.28*	0.61†	-0.26*
		GI/digestive	-0.47†	-0.04	-0.15	0.31*	-0.26*
		Excretion	-0.22*	-0.06	-0.13	0.20*	-0.14
		Physical comfort	-0.62†	0.02	-0.15	0.38†	-0.18
		Support	0.26*	0.18	0.37†	-0.20*	0.42†
		Positive outlook	0.60†	0.16	0.36†	0.49†	0.40†

\* $P < 0.01$ ; † $P < 0.001$ . Internal consistency and test-retest reliabilities of the LEQ scales are also shown.

Table 4. Mean subscale scores by age group ( $\pm$  S.E.M.)

			Age group (years)			
			Range	<50	50-65	>65
LEQ	Freedom	0-60 (7-54)	31.8 ± 1.6	33.2 ± 1.0	34.4 ± 1.1	
	Appreciation of life*	0-48 (1-30)	19.2 ± 1.0‡	18.2 ± 0.6‡	16.2 ± 0.8	
	Contentment	0-54 (3-48)	35.2 ± 1.5	35.8 ± 0.9	37.2 ± 1.0	
	Resentment*	0-78 (0-66)	36.2 ± 2.6‡	30.4 ± 1.6‡‡	27.3 ± 1.7‡	
	Social integration	0-48 (12-48)	40.1 ± 1.3	39.6 ± 0.7	40.6 ± 0.8	
RSCL	Physical	0-57 (2-43)	17.9 ± 1.5	18.0 ± 0.9	17.3 ± 1.0	
	Psychological	0-24 (0-23)	8.3 ± 0.8	8.2 ± 0.7	7.0 ± 0.6	
MacAdam and Smith	Mood	0-12 (0-12)	2.9 ± 0.3	3.0 ± 0.3	2.8 ± 0.3	
	Fear*	0-12 (0-11)	4.4 ± 0.5‡	3.3 ± 0.2‡‡	2.5 ± 0.2‡	
	GI	0-12 (0-10)	3.8 ± 0.4	3.3 ± 0.3	3.2 ± 0.3	
	Knowledge	0-12 (1-12)	9.7 ± 0.4	9.8 ± 0.3	9.5 ± 0.3	
	Support	0-12 (1-12)	9.5 ± 0.4	9.6 ± 0.3	9.4 ± 0.3	

\* $P < 0.05$ , possible (and actual) ranges of scores are also shown; †Differs from youngest age group; ‡Differs from oldest age group ( $P < 0.05$ ).

Two other scales correlated only modestly with the other instruments. 'Social integration' refers, not simply to present social support (although its highest convergent validation is with the MacAdam and Smith 'Support' scale), but also to an evaluation of social relationships in the past. 'Contentment' describes the degree of satisfaction with life and is therefore not simply a positive mood scale; its correlations with psychological symptoms (RSCL) and mood scales derived from MacAdam and Smith's questionnaire are correspondingly modest.

Inspection of the two scales which overlap most clearly with

existing ones also indicates a difference in emphasis. 'Freedom from restriction' clearly relates highly to the symptom-based RSCL scales but emphasises, not merely the experience of symptoms, but the degree to which they restrict life versus the degree to which life plans continue uninterrupted. Similarly, although 'having symptoms that bother me' loads on 'Resentment', and although this scale correlates with the RSCL scales, it does not describe a conventional picture of passive suffering so much as a pre-occupation with illness and a resentment at its effect on life.

The way in which LEQ scores varied with patients' age

provided further validation for two of its scales. As predicted, younger patients both gained more appreciation of life from their illness and felt more resentful of it. Both results can be attributed to the greater developmental readjustment necessary for the young patients when compared with older patients who had already confronted their own mortality. One MacAdam and Smith scale, Fear, detected greater emotional distress in younger patients; the RSCL detected no age effects whatsoever. Clearly, the LEQ detects dimensions of the experience of incurable illness to which even the MacAdam and Smith scale is insensitive. This vindicates our derivation of items from the in-depth interviewing of patients, whereas MacAdam and Smith [18] derived items mainly from professionals.

The percentage variance explained by our items was modest, but similar to analyses of the RSCL [4]. Although the percentage is omitted from some reports, higher values have been explained in other analyses; however, this is to be expected as the items for these were more homogeneous than ours, being chosen because of their relevance to symptoms and function [21, 22]. Even where items have been based on wide-ranging interviews with patients, the emphasis on brief interviews of large numbers has led to a restricted coverage of the meaning of illness [23]. Clearly, the LEQ does not provide a complete assessment of a patient's psychological reaction to illness. In particular, references to illness-specific symptoms were excluded at the outset and anxiety and depression items were excluded on the basis of the analysis. Instead, the questionnaire focuses on patients' evaluation of the effect of their symptoms on their lives. More conventional scales, based on physical and emotional symptoms, should therefore be included if a complete assessment of quality of life is sought. Nevertheless, the reliability values are high and indicate that the aspects of life evaluation that the LEQ does measure are measured accurately.

Further validation of the LEQ should include its use in other cultural and religious groups, to whom our analysis cannot be assumed to generalise. The scale should also be compared with quality of life inventories in use in cancer trials, as well as with other scales measuring purpose or meaning of life. This could include comparison with a scale reported by Cohen and associates [24] after the present study was completed. This was based on the analysis of responses of a modest sample ( $n = 40$ ) to questions chosen on the basis of previous literature rather than in-depth interviews of patients. Nevertheless, the scale yielded components which may be related to ours because they describe positive feelings about life and its meaning. It is not yet clear whether our scale would be sensitive to symptomatic treatments, but it is very likely to be useful to assess treatments targeted on adaptation to, and the meaning of, illness such as counselling and psychotherapy. A separate function of this scale could be to identify areas of concern on which psychological treatments could focus. Many patients spontaneously welcomed the opportunity which this study provided to voice concerns which they had not previously expressed because of a perception that hospital staff preferred not to be burdened with such disclosures. In the U.K., psychological adjustment to a diagnosis of incurable cancer has been identified by the NHS health services research strategists as a priority area for research. The Life Evaluation Questionnaire can provide a unique tool in this important and relatively unexplored area of palliative care.

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**Acknowledgements**—For permission to study their patients, we thank Professors S. Bown, A. Lynch and R. Souhami and Drs A. Cassoni, G. Duchesne, S. Harland, J. Lederman, S. Spiro, M. Spittle and J. Tobias. We are grateful to Drs C. Barker, S. Greer, L. Fallowfield, E. Parker, N. Pistrang and Ms S. Marchant-Haycox for their advice, to Dr Eli Jaldow for help with the interviews and to the Middlesex Hospital Special Trustees for financial support.