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Assessment of health status in survivors of cancer

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Abstract

The health status of 48 survivors of cancer was assessed using a rating system for six attributes: senses, mobility, emotion, cognition, self care, and pain. Paired assessments were made by doctors and patients (or their parents, or both) at routine clinic attendances. Sixteen (33%) assessments by the patient/parent and 19 (40%) assessments by the doctor identified no deficits in health status. The doctors identified fewer deficits in all attributes than the patients/parents, the differences being most marked for subjective attributes. Health status index scores on a scale of 0 (worst health state) to 1 (perfect health) were derived from the rating system and showed good overall agreement between the doctors and the patients/parents. Survivors of neuroaxial tumours tended to have lower scores than other diagnostic groups. This simple, compact system could be used in clinical trials to compare treatment strategies in terms of the health status of survivors. It could also be a valuable tool in the assessment of health status in other areas of paediatrics.

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The improved survival of patients with childhood cancers has led to increasing concern about the long term effects of the disease and its treatment on the health status of the survivors. A wealth of information has been published on a wide variety of sequelae[1–7] but, until recently, there has been no comprehensive method of assessing the overall health status of these children. Most children are now treated within clinical trials and there is a need for a method of assessment which will allow treatment strategies to be evaluated, not only in terms of improved survival, but also in terms of the health status of the survivors. In 1992 Feeney *et al* described a 'comprehensive multiattribute system' which uses seven attributes to assess health status: senses, mobility, emotion, cognition, self care, pain, and fertility.[8] The first six attributes have been identified by previous research as being the most important dimensions of health status to parents and children.[9 10] Fertility was added because of the well documented problems of subfertility and infertility after chemotherapy and radiotherapy. Each attribute in this system is subdivided into levels and focuses on functional capacity rather than performance. Therefore the system is designed to assess the extent to which deficits in health status for each attribute inhibit or prohibit normal functioning.

This system has been linked to a system of preference scores developed by Torrance *et al.*[11] They conducted a survey among about 300 parents of normal children in Hamilton, Canada in 1987, asking them to rate different health states in order of preference – for example, did they feel that having severe pain but no other deficits was worse than having a combination of deficits in mobility and self care. From these ratings utility functions were derived for each level of the system of Feeny *et al.*[8] Using a combination of these utility functions it is possible to provide a single health status index score for each patient on a scale of 0 (worst health state) to 1 (perfect health).

This report describes a prospective study of the application of this system in a British paediatric oncology clinic. This is the first study to collect paired assessments of health status using this system rated by doctors and patients (or their parents, or both), and we investigate how well they agree.

Methods

All 63 oncology patients who had completed their treatment and who attended 10 clinics at the University Hospital, Nottingham between January and April 1993 were eligible to be included. Patients were seen by one of three doctors. The health status assessment system described by Feeny *et al*[8] was used with some modifications, mainly to make the language more easily understood by lay subjects (table 1). An initial pilot study suggested that the wording of the 'emotion' section was confusing for parents and patients and this was therefore simplified, though the grading of the levels was retained. The fertility section was omitted as we felt that this was impossible to assess in our paediatric study group. The consultation with the doctor was informally structured to enable the doctor to assess the child's health status in each of the six attributes and after each consultation the doctor immediately completed the assessment. If a child was seen more than once during the study period the assessment was only completed on one occasion.

For patients less than 8 years old the parent accompanying the child was asked to complete a second assessment after being seen by the doctor. For patients aged 8–14 years the parent and the child were asked to complete the second assessment together, and for patients older than 14 years the patient was asked to complete the assessment with help from a parent only if they felt it necessary. For the assessment by the patient/parent, a further section was added to assess the overall degree of satisfaction with life. This asked the question: 'on a scale of 1–5 how satisfied are

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Table 1 Multiattribute health status classification system. Adapted from Feeney et al.[8] *The respondents are asked to circle the most appropriate number for each attribute*

Attribute	*Level*	*Description*
1. Senses	1	Ability to see, hear, and speak normally for age
	2	Requires equipment to see, hear, or speak (e.g. glasses, hearing aid)
	3	Sees, hears, or speaks with limitations even with equipment
	4	Blind, deaf, or mute
2. Mobility	1	Able to walk, bend, lift, jump, and run normally for age
	2	Walks, bends, lifts, jumps, or runs with some limitations but does not require help
	3	Requires mechanical equipment (such as walking stick, crutches, braces, or wheelchair) to walk or get around independently
	4	Requires the help of another person to walk or get around and requires mechanical equipment as well
	5	Unable to control or use arms and legs
3. Emotion*	1	Happy and sociable
	2	Occasionally unhappy/moody
	3	Often unhappy/moody
	4	Mostly miserable
	5	Withdrawn and unhappy
4. Cognition	1	Learns and remembers schoolwork normally for age
	2	Learns and remembers schoolwork more slowly than classmates as judged by parents or teachers, or both
	3	Learns and remembers very slowly and usually requires special educational assistance (e.g. special school, individual lessons)
	4	Unable to learn and remember
5. Self care	1	Eats, bathes, dresses, or uses the toilet normally for age
	2	Eats, bathes, dresses, or uses the toilet independently but with more difficulty than expected for age
	3	Requires mechanical equipment to eat, bathe, dress, or use the toilet independently
	4	Requires the help of another person to eat, bathe, dress, or use the toilet which would not be expected for age
6. Pain	1	Free of pain and discomfort
	2	Occasional pain without disruption of normal activities
	3	Frequent pain. Discomfort relieved by drugs taken by mouth, e.g. paracetamol, with the occasional disruption for normal activities
	4	Frequent pain. Frequent disruption of normal activities. Discomfort requires prescription drugs for relief (e.g. morphine, codeine)
	5	Severe pain. Pain not relieved by drugs and constantly disrupts normal activities

*Descriptions for emotion levels from original system: 1=generally happy and free from worry; 2=occasionally fretful, angry, irritable, anxious, depressed, or has night terrors; 3=often fretful, angry, irritable, anxious, depressed, or has night terrors; 4=almost always fretful, angry, irritable, anxious, depressed, or has night terrors; and 5=extremely fretful, angry, irritable, or depressed, usually requiring admission to hospital or psychiatric institutional care

Table 2 Number of children with affected attributes

No of attributes affected (doctor's assessment)	*No of attributes affected (patient's or parent's assessment)*							*Total No (%) of children*
	0	*1*	*2*	*3*	*4*	*5*	*6*	
0	11	3	3	2	0	0	0	19 (40)
1	4	7	5	2	2	0	0	20 (42)
2	1	1	2	1	1	0	0	6 (13)
3	0	0	0	0	1	0	0	1 (2)
4	0	0	1	0	0	0	0	1 (2)
5	0	0	0	0	0	0	0	0 (0)
6	0	0	0	0	0	1	0	1 (2)
Total No (%) of children	16 (33)	11 (23)	11 (23)	5 (10)	4 (8)	1 (2)	0 (0)	48 (100)

you with your (if you are the patient) or your child's life?' (1=very, 5=not at all).

Assessments were completed by the patient/parent and the doctor in 48 (76%) of 63 children seen. Six children were excluded as it was felt by the doctor to be an inappropriate time to ask the patients/parents to be included in a study – for example, a probable relapse diagnosed during that clinic visit. No patient or parent refused to be included in the study, but one child was accompanied by a nanny who felt that the parents would not wish her to complete the assessment in their absence. Two children were excluded because the assessments were incomplete (the parents did not realise that the assessment continued over the page) and in the remaining six cases the patient left the clinic before being asked to complete the assessment. The study group included survivors from the following diagnostic groups: acute lymphoblastic leukaemia (17), brain tumour (seven), non-Hodgkin's lymphoma including one presenting in the spine (six), rhabdomyosarcoma (six), Wilms' tumour (four), Hodgkin's disease (two), neuroblastoma (two), osteosarcoma (one), hepatoblastoma (one), teratoma (one), and Ewing's sarcoma (one). There were 28 boys and 20 girls aged between 2 and 17 years (five less than 5 years, 13 aged 5–7 years, 19 aged 8–14 years, and 11 older than 14 years). The time since the end of treatment ranged from one month to 12 years (median less than one year).

Results

A total of 48 assessment pairs was collected. Parents, patients, and doctors all found the assessment quick and simple to complete, taking doctors about two minutes and patients/parents no more than five minutes.

Sixteen (33%) of the assessments by the patients/parents and 19 (40%) of the doctor's assessments identified no deficits in any of the six attributes (table 2). Of the children identified as having a deficit, most had a deficit in only one or two attributes. One patient was assessed by the doctor as having a deficit in all six attributes. The same patient was felt to have no deficit in cognition by her mother, but deficits in all other attributes.

The assessments by the doctor identified fewer deficits than the assessment by the patient/parent in all categories and the difference was greatest in the pain category (fig 1). In only seven children did the doctor feel that the patient had pain: four with occasional pain without disruption of normal activities; two with frequent pain; and one with severe pain. Sixteen patients/parents reported pain: 13 with occasional, two with frequent, and one with severe pain.

For 17 children there was no difference between the assessment by the doctor and that by the patient/parent of health status. Where there was disagreement between the two assessments, most disagreed on either one or two attributes only (15 and 10 children respectively), and in all but three patients they differed by only one level. The doctor and

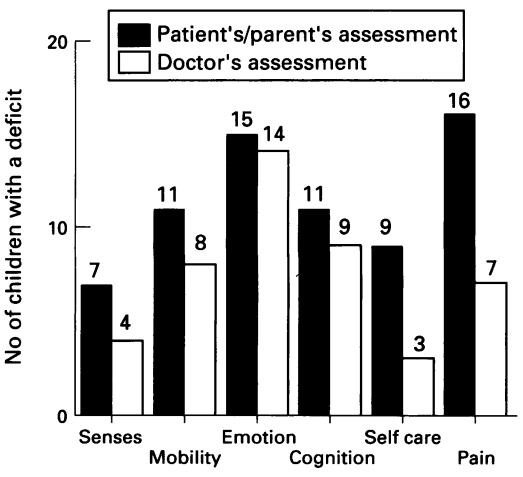

Figure 1 Occurrence of deficits in each attribute as assessed by the patient/parent and doctor.

Table 3 Preference based utility functions assigned to each level of the six attributes. Adapted from Torrance et al[11]

Level of attribute	*Sensation* (b_1)	*Mobility* (b_2)	*Emotion* (b_3)	*Cognition* (b_4)	*Self care* (b_5)	*Pain* (b_6)
1	1·00	1·00	1·00	1·00	1·00	1·00
2	0·95	0·97	0·93	0·95	0·97	0·97
3	0·86	0·84	0·81	0·88	0·91	0·85
4	0·61	0·73	0·70	0·65	0·80	0·64
5	–	0·58	0·53	–	–	0·38

The health status index score (u) on a utility scale of 0·00 (worst health state) to 1·00 (perfect health) is obtained using the formula: $u = 1{\cdot}06\ (b_1 \times b_2 \times b_3 \times b_4 \times b_5 \times b_6) - 0{\cdot}06$, where b_i is the preference based utility function for each level of attribute i.

patient/parent most often differed in their assessment of the subjective attributes of pain and emotion (fig 2).

The results were analysed using the preference based health status index scoring system devised by Torrance *et al*[11] (table 3).

The health status index scores assessed by the patient/parent ranged from 0·29 to 1·00 (median 0·93). The scores assessed by the doctor ranged from 0·31 to 1·00 (median 0·96). Using the Wilcoxon test for paired data there was no significant difference between the two health status scores. These results are illustrated in a scatter diagram (fig 3), which shows a marked discrepancy in score for only two patients. Patient A, a girl with a spinal non-Hodgkin's lymphoma, was rated by her mother as having a more severe deficit in mobility and self care than by the doctor, and the mother reported frequent pain which the doctor did not identify. Patient B, a boy with a rhabdomyosarcoma of the common bile duct, was rated by both doctor and parent as only having a deficit in the pain category, and interestingly the doctor rated this as more severe than the mother.

Table 4 shows the median index score and range for each diagnostic group; the patients with neuroaxial tumours tended to have lower scores than the other groups, particularly when rated by the patient/parent. The numbers in each group, however, are too small for this to be statistically significant.

Most patients/parents were very satisfied with their or their child's life (31/47 (66%); one patient omitted this section). These 31 patients had index scores assessed by the patient/parent of 0·83–1·00 (median 0·93). Only one child's parents were not at all satisfied with their daughter's life (index score assessed by parent 0·36). Fifteen respondents circled either 2 or 3 on the scale of satisfaction (index scores assessed by patient/parent 0·29 to 1·00; median 0·85). There was no statistically significant correlation between health status index score and satisfaction in this sample and larger studies are needed to assess whether a correlation exists.

Table 4 Preference based health status index scores for each diagnostic group

Diagnosis (No of cases) (n=48)*	*Median (range) health status index score*	
	Patient's or parent's assessment	*Doctor's assessment*
ALL (17)	0·92 (0·80–1·00)	0·95 (0·82–1·00)
NHL (excluding spinal) (5)	0·89 (0·85–1·00)	0·97 (0·93–1·00)
CNS tumours including spinal NHL (8)	0·69 (0·29–0·97)	0·88 (0·31–1·00)
Wilms' tumour (4)	0·95 (0·78–1·00)	0·97 (0·93–1·00)
Osteosarcoma (1)	0·86	0·84
Rhabdomyosarcoma (6)	0·91 (0·84–1·00)	0·99 (0·62–1·00)
Hodgkin's disease (2)	0·99 (0·97–1·00)	0·95 (0·89–1·00)
Hepatoblastoma (1)	0·95	1·00
Teratoma (1)	1·00	1·00
Ewing's sarcoma (1)	1·00	0·89
Neuroblastoma (2)	1·00	1·00

*ALL=acute lymphoblastic leukaemia; NHL=non-Hodgkin's lymphoma; CNS=central nervous system.

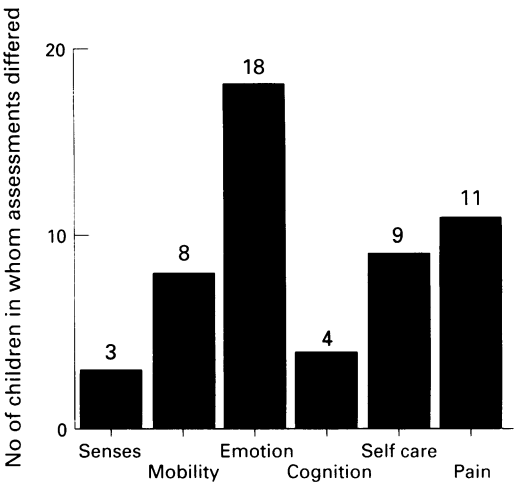

Figure 2 Attributes in which disagreement occurred between the assessment of the patient/parent and the doctor.

Discussion

We have described the application of a system which uses six attributes (senses, mobility, emotion, cognition, self care, and pain) to assess the overall health status in 48 survivors of childhood cancer. For each patient, paired assessments were made by a doctor and the patient (or the parent, or both) and all found the system simple and quick to use. This confirms the findings of Feeny *et al* who tested their system in small surveys of patients who were receiving or who had completed treat-

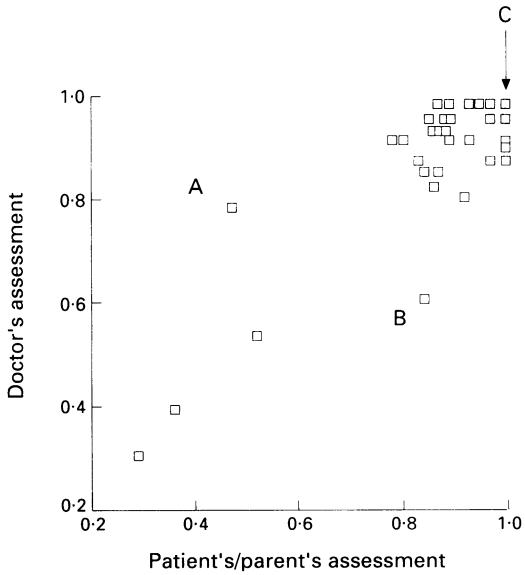

Figure 3 Scatter diagram of health status index scores showing good agreement between the assessment of the patient/parent and the doctor. Points A and B: see text. Point C represents 11 patients with index scores of 1·00, 1·00; two patients represented by each of points 1·00, 0·93 and 0·87, 1·00; and three patients represented by each of points 0·93, 0·93 and 0·89, 1·00.

ment[8] and in a larger, retrospective study of 69 survivors of high risk acute lymphoblastic leukaemia.[12] We integrated the assessments into routine clinic attendances, whereas, in their larger study, Feeny *et al*[8] adopted a case note review process to obtain data.

We applied the system to many different disease groups and this has identified an interesting trend, confirming the clinical suspicion that the health status outcome for survivors of neuroaxial tumours is worse than for other groups. Feeny *et al*[8] used vectors to describe the health status of each patient (x_1, x_2, x_3, x_4, x_5, x_6, x_7), where x_i describes the level (1–5) for attribute i, but Torrance *et al*[11] have linked the system to preference based utility functions, which combine to provide a single health status index score for each patient on a scale of 0 (worst health state) to 1 (perfect health). We used this single index score to describe each patient's health status as it is obviously more useful for comparison between groups than a vector.

Feeny *et al* found good agreement between independent ratings by doctors.[8] We found no significant difference between the paired index scores derived from the two assessments in our study, but the doctors identified fewer deficits in all attributes than patients/parents, the differences being most marked for subjective attributes. Whether it is appropriate to use these index scores depends on the study of Torrance *et al* and their weighting of the utility functions. British parents may have different views from those in Canada and may give different weighting to each health state. We should, perhaps, repeat the survey of Torrance *et al*[11] in the UK to validate the utility functions applied to our system.

With improved survival from childhood cancer, death is a less powerful endpoint in clinical trials and further attempts to improve treatment strategies will need to consider the health status of the survivors, particularly for children with brain tumours. There is a great need for a simple, comprehensive system of assessment of the health status for children. Formal psychometric-neurological assessments have been used in some studies[13] but these are time consuming and require specialist application, and so are not useful in routine follow up clinics. They also focus on performance rather than functional capacity and therefore rely on patient cooperation. Many methods of assessment have been developed for adults such as the Karnofsky performance scale,[14] Katz's activities of daily living index,[15] the sickness impact profile,[16] the short form 36 (SF-36) health survey questionnaire,[17] and the Nottingham health profile,[18] but none has been found to be suitable for children. The Karnofsky scale was originally designed for use with patients with lung cancer and uses a simple scale from 1 to 100 (normal to moribund). It is heavily weighted towards physical ability rather than social or psychological dimensions. Several attempts have been made to modify the Karnofsky scale to apply to children, including a four point scale of performance ranging from no disability to total disability,[19] and a scale using school attendance as a measure of wellbeing.[20] These give only a general assessment of health status and have not been widely used.[20] The activities of daily living index was designed to describe the functional abilities of elderly patients in areas such as bathing, dressing, transferring, toileting, and continence, and again focuses on physical ability. The sickness impact profile is a broader measure of health status but is lengthy, containing 136 items, and includes items referring to dysfunction in areas such as employment and housework. The SF-36 and the Nottingham health profile are shorter, but are again geared towards adult activities. The Nottingham health profile provides only a limited measure of function, and some disabilities are not assessed at all (for example, sensory deficits).

The only validated scale for children is the Lansky play scale[21] and this has been used in several clinical trials. The scale records the usual play activity as an index of performance and includes 10 graded statements. Examples of these statements include: 100 (fully active, normal); 50 (gets dressed but lies around much of the day, no active play, able to participate in all quiet play and activities); 20 (often sleeping, playing entirely limited to very passive activities); and 0 (unresponsive). This may be useful as a measure of wellbeing, particularly during treatment, but does not give a comprehensive assessment of health status which can be used to evaluate outcome. Other methods included in clinical trials are developmental scales (for example, the Denver scale), intellectual assessments (for example, the Weschler scales), and behaviour checklists, but again these are not comprehensive and several different methods need to be used to give an overall measure of health status.

The system of Feeny *et al*[8] is comprehensive and includes the attributes that have been identified by previous research as being the most important dimensions of health status to parents and children.[9 10] The system assesses health status and we have deliberately avoided using the term 'quality of life' as we feel this is a subjective concept and is difficult to define. We included the 'satisfaction' scale as a general assessment of the overall satisfaction with life; larger studies are needed to assess whether this correlates with health status. We have adapted the system of Feeny *et al*[8] to allow patients and parents to complete the assessment. It has previously only been used by doctors and we found it necessary to modify some of the language such as changing 'prescription narcotics' to 'prescription drugs e.g. codeine or morphine' in level 4 of the pain section. In an initial pilot study we found much confusion with the emotion section. Parents and patients found it difficult to distinguish between the levels 2, 3, and 4, the only difference being the description 'occasionally', 'often', and 'almost always'. They seemed to be confused by the long list of adjectives that followed, even though they were identical for each level. Some parents also felt that night

terrors were not abnormal in a preschool child. We therefore modified the section, making the sentences shorter and retaining the 'occasionally' and the 'often', but changing 'almost always' to 'mostly'. This modified section was easily understood. We felt that the grading of the levels was maintained and that we were therefore justified in using the preference based utility functions assigned to the original system.

In previous studies this system has only been used for children older than 7 years and it may need to be modified for younger children. In particular, modification of the cognition section for children of preschool age may be necessary to reduce the emphasis on performance at school. In our study, however, all five preschool children were felt to have normal cognition for their age by the doctors and parents and so were rated as level 1. The self care section was more readily understood with the addition of the words '. . . but with more difficulty than would be expected for age' to level 2 and '. . . which would not be expected for age' to level 4. There is a wide range of abilities which are normal for age, however, particularly in the preschool age group.

The overall agreement between the paired assessments is not surprising as the doctor's rating was based on the report of the patient/parent during the consultation and previous knowledge of the patient, as well as on clinical examination. The differences between ratings were most marked for the subjective attributes as would be expected from previous work,[22] but in most instances they differed by only one level.

It is interesting that the doctors identified fewer deficits in all categories and this confirms the observation that proxy respondents who are not familiar with the patient tend to understate health problems compared with self reporting by the patient.[22] Over-reporting by parents who are understandably anxious about their children may also be an important factor. Previous work suggests that carers acting as proxy respondents for the elderly tend to overestimate patient disability relative to the patients themselves[22 23] and it may be that observers give more weight to negative rather than positive information when forming impressions of others.[24]

As Feeny *et al* have highlighted,[8] the system is comprehensive but not exhaustive, with several important components of patient follow up such as organ toxicity and prognosis omitted. It remains a useful tool in the overall assessment of health status, however. Application of this system is not limited to survivors of cancer but could be valuable in the assessment of survivors of neonatal intensive care and children with chronic disorders such as cystic fibrosis.

In conclusion, this system provides a compact assessment of health status which can be completed by the patient, parent, or doctor. It is simple and not time consuming and could therefore be incorporated into clinical trials of cancer treatment designed to evaluate the impact of treatment during and after its completion. To detect a 0·1 difference in index score between two treatment arms with 95% power would require between 80 and 180 patients in each arm. Changes in health status could be readily documented by serial application. Studies with larger numbers in each diagnostic group are needed to investigate differences in outcome, particularly between children with brain tumours and those with other cancers.

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