ORIGINAL ARTICLE

The Health Status Questionnaire: achieving concordance with published disability criteria

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Aim: To compare the Health Status Questionnaire with established methods of assessing disability in preterm and very low birthweight infants.

Method: All survivors of gestational age <31 weeks or birth weight <1500 g, born in 1994 to women resident in Wales were identified. Assessments were by a single observer at a median corrected age of 28.3 months and included the Health Status Questionnaire and a Griffiths developmental test. Outcome was also described according to criteria for disability used in three published studies.

Results: There were 297 survivors of which 279 (94%) were assessed. Using the Health Status Questionnaire, severe disability was found in 12.9% of cases compared to 8.2%, 2.9%, and 3.6% using the Northern, Victorian, and Mersey outcome criteria respectively. Following the simple modifications of removing the growth criteria from the Health Status Questionnaire and reclassifying the severe disability group in the Victorian and Mersey criteria, comparable severe disability rates ranging from 7.9% to 9.3% were found.

Conclusion: The Health Status Questionnaire requires no formal training, is rapid to perform, and with simple modifications provides comparable results to established methods of assessing disability. Its use in the follow up of preterm and very low birthweight infants should be encouraged.

The main purpose of neonatal intensive care is to promote healthy survival. In recent years advances in perinatal medicine, such as the widespread use of antenatal steroids and exogenous surfactant therapy, have led to notable improvements in birth weight and gestation specific survival, so that a substantial number of infants previously considered previable now survive.[1–4] However, there is concern that in some cases, new therapies simply aid the survival of infants who have suffered a range of insults resulting in later disability.[5–7]

A review of published follow up studies shows considerable variation in the reported outcome for very preterm infants, with the proportion of survivors having a major disability ranging from 6% to 23%.[5–9] Some of this variation may reflect differences in the quality of perinatal care, but it may also be a consequence of population bias and differences in methodology. Studies from specialised units may report different disability rates than those of geographically defined populations because of variations in the criteria used for referral, admission, and treatment. More importantly there are differences in the definition and grading of disability between studies, often making direct comparisons impossible. Moreover, the formal neurodevelopmental tests (most commonly the Griffiths Test and Bayley Scales) used in many follow up studies, require formal training and are time consuming to perform. This inevitably makes such tests too expensive to be widely used as methods of routine or even research based follow up assessment of high risk infants.

The Health Status Questionnaire was developed as an alternative method of assessing outcome by a working group set up in 1994 by the National Perinatal Epidemiology Unit and the Oxford Regional Health Authority.[10] It was intended as a method of routine assessment for all children at 2 years of age, and in contrast to established methods, requires no formal training and is rapid to use. Nevertheless, its value as a method of determining impairment and disability in a high risk population has not been tested. The objective of this study was to compare the performance of the Health Status Questionnaire with established methods of assessment in detecting impairment and disability in a geographically defined population of preterm and very low birthweight infants.

SUBJECTS AND METHODS

Subjects

All infants with a birth weight less than 1500 grams or gestational age less than 31 weeks born to women normally resident in Wales in 1994 were included in the study. Live births were identified using the Welsh Child Health System database, and survival to 1 year of age established using the All Wales Perinatal Survey. Continued survival to 2 years of age was confirmed in each case by contacting the general practitioner or health visitor. A study information pack was then sent to the parents, requesting their kind participation. Following completion of the assessments, background obstetric and neonatal data were obtained from hospital case notes.

Assessments

All assessments were performed by a single observer (HPJ) over the course of 12 months. The median age (corrected for gestational age at birth) at the time of assessment was 28.3 months. Tests were conducted in English or Welsh, depending on the first language in the household and parental wishes. The Health Status Questionnaire examines eight clinical domains, each with specific criteria for severe disability (table 1). Most of the data were collected by direct questioning of the parents, followed by a clinical examination of the child, with specific emphasis on neuromotor function and growth parameters. Height was measured using the portable Leicester Height Measure (Child Growth Foundation, Chiswick,

Abbreviations: DQ, developmental quotient

Table 1 The Health Status Questionnaire: criteria for impairment and disability

Domain Key questions	Criteria for impairment or disability (criteria for severe disability in bold)
Malformation	
Does the child have a malformation?	Any anomaly detected at birth or apparent within the first two postnatal years, which is likely to result in death, disfigurement or disability, and which is likely to require medical or surgical treatment (other than a simple cosmetic procedure) **Any malformation which despite physical assistance impairs the performance of daily activities**
Neuromotor function	
Does the child have any difficulty walking?	Non-fluent gait Abnormal gait reducing mobility **Unable to walk without assistance**
Does the child have any difficulty sitting?	Sits unsupported but unstable Sits supported **Unable to sit**
Does the child have any difficulty with hand use?	Some difficulty feeding with one hand Some difficulty feeding with both hands **Unable to use hands to feed self**
Does the child have any difficulty with head control?	Unstable but no support required **Unable to control head movement without support** **No head control**
Seizures	
Does the child have seizures?	No treatment required No seizures on treatment Seizures less than 1/month despite treatment **Seizures more than 1/month despite treatment**
Auditory function	
Does the child have any difficulty hearing?	Hearing impaired, not aided Hearing impaired, corrects with aids **Hearing impaired, uncorrected even with aids**
Communication	
Is there any difficulty with communication?	Unable to comprehend word/sign out of familiar context **Unable to comprehend word/sign in cued situation** Uses single words only/vocabulary >10 words Vocabulary <10 words **Unable to produce >5 recognisable sounds** **No vocalisation**
Visual function	
Does the child have any difficulty with vision?	Normal vision with correction Not fully correctable **Blind or sees light only**
Cognitive function	
Does the child have any learning difficulty?	Developmental quotient 2 to 3 SD below mean **Developmental quotient >3 SD below mean**
Other physical disability	
Does the child have any other disability?	Limited exercise tolerance, no drug treatment
Respiratory	Limited exercise tolerance, on drug treatment **Requires continual oxygen therapy** **Requires mechanical ventilation**
Gastrointestinal	Requires special diet Has stoma **Requires tube feeding** **Requires parenteral nutrition**
Renal	Renal impairment; no treatment Renal impairment; drug or dietary treatment only **Requires dialysis**
Growth	Height or weight 2 to 3 SD below mean for age **Height or weight >3 SD below mean for age**

London) and weight using electronic scales (Salter Ltd). Binocular visual acuity was assessed using the Cardiff Visual AcuityCards (Keeler Ltd). Cognitive function was assessed using the Griffiths Mental Developmental Test[11 12] to derive the developmental quotient (DQ). Where available, the results of other hearing and vision tests were also recorded.

Classification of disability

The Health Status Questionnaire identifies difficulties in each clinical domain and depending on severity, cases are classified into one of three outcome groups:

- Severe disability—severe disability in one or more clinical domains
- Impairment without severe disability—difficulties in one or more clinical domains which do not meet the criteria for severe disability
- Normal—no difficulties in any clinical domain.

Cases were also classified into outcome groups using three different methods of defining and categorising disability recently used in published follow up studies from the UK and Australia. These three were specifically selected as

Table 2 Criteria for disability: established methods

Northern criteria		Victorian criteria		Mersey criteria	
Severe disability	Cerebral palsy severe enough to hamper age appropriate activity	**Severe disability**	Cerebral palsy—unlikely to walk	**Severe disability**	For example:
	Deafness warranting a hearing aid		Bilateral blindness		Spastic quadriplegia
	Blindness or partial sight		Developmental index 3SD or more below the mean		Blindness
	Developmental quotient <70				Deafness
	Epilepsy uncontrolled by drugs				Epilepsy—uncontrolled
	Permanent stoma				Developmental quotient <50
					Multiple disabilities
Impairment without disability	Mild cerebral palsy	**Moderate disability**	Cerebral palsy—non-ambulant but likely to walk	**Moderate disability**	For example:
	Developmental quotient 70–79		Sensorineural deafness requiring amplification		Spastic diplegia or hemiplegia
					Developmental quotient 50–69
Minor impairment	Squint	**Mild disability**	Cerebral palsy—ambulant	**Mild disability**	For example:
	Growth retardation after bowel resection		Developmental index between 1SD and 2SD below the mean		Myopia, language delay, mild hearing loss, hyperactivity, motor clumsiness
	Speech delay with hearing loss				
Normal	None of the above	**Normal**	None of the above	**Normal**	None of the above

Table 3 Outcome according to four methods for defining disability

Health Status criteria		Northern criteria		Victorian criteria		Mersey criteria	
Severe disability	36 (12.9%)	**Severe disability**	23 (8.2%)	**Severe disability**	8 (2.9%)	**Severe disability**	10 (3.6%)
Impairment without severe disability	68 (24.4%)	**Impairment without disability**	6 (2.2%)	**Moderate disability**	15 (5.4%)	**Moderate disability**	16 (5.7%)
	—	**Minor impairment**	15 (5.4%)	**Mild disability**	10 (3.6%)	**Mild disability**	12 (4.3%)
Normal	175 (62.7%)	**Normal**	235 (84.2%)	**Normal**	246 (88.2%)	**Normal**	241 (86.4%)

outcome criteria were clearly defined and the population studied and timing of assessment were similar to ours (very preterm or very low birthweight infants assessed at 2–3 years). With reference to the regions where these studies took place, they have been termed the Northern criteria,[8] the Victorian criteria,[6] and the Mersey criteria[9] (table 2). Comparisons were made between the results of all four methods.

Statistical analysis was performed using SPSS version 7.5.[13] Approval for the study was given by all the local research ethics committees in Wales and informed written parental consent was obtained in each case. Parent information and consent forms were available in English and Welsh.

RESULTS

There were 35 451 liveborn infants in Wales during 1994. A total of 414 infants were less than 31 weeks gestation or had a birth weight less than 1500 g; 90 died in the first 28 days of life (79 in the first week) and 27 died later during the first two years. There were therefore 297 (72%) long term survivors eligible for inclusion in the study. In 16 cases the parents declined to participate; two children proved untraceable and were lost to follow up. A total of 279 (94%) children were assessed. All were seen at the family home except for two cases assessed at a local health centre.

Severe disability using the Health Status criteria was present in 36 (12.9%) children, compared with 23 (8.2%) using the Northern criteria, eight (2.9%) using the Victorian criteria, and 10 (3.6%) using the Mersey criteria (table 3). More children were classified as having an "impairment without severe disability" using the Health Status Questionnaire, so criteria for normality were met by only 175 (62.7%) children, compared with 235 (84.2%) using the Northern criteria, 246 (88.2%) using the Victorian criteria, and 241 (86.4%) using the Mersey criteria.

Since impairment and disability rates varied widely depending on the criteria used, a review of the definitions was undertaken with the aim of establishing more comparable outcome groups. Some of the difference was a result of the inclusion of disability based on poor growth in the Health Status Questionnaire. This was not taken into consideration by the other methods. When the growth domain was excluded from analysis, disability rates using the Health Status criteria were more comparable to the other methods, with severe disability in 22 (7.9%) children and impairment without severe disability in 42 (15.1%) (table 4).

Furthermore, the number of children classified as severely disabled was much lower using the Victorian

Table 4 Outcome according to revised criteria for disability

Health Status criteria		Northern criteria		Victorian criteria		Mersey criteria	
Severe disability	22 (7.9%)	**Severe disability**	23 (8.2%)	**Severe and moderate disability**	23 (8.2%)	**Severe and moderate disability**	26 (9.3%)
Impairment without severe disability	42 (15.1%)	**Impairment without disability and minor impairment**	21 (7.5%)	**Mild disability**	10 (3.6%)	**Mild disability**	12 (4.3%)
Normal	215 (77.1%)	**Normal**	235 (84.2%)	**Normal**	246 (88.2%)	**Normal**	241 (86.4%)

Table 5 Concordance between Health Status and Northern criteria

	Northern criteria			
Health Status criteria	Normal	Impairment	Severe	Total
Normal	209	6	–	215
Impairment	25	15	2	42
Severe	1	–	21	22
Total	235	21	23	279

κ statistic = 0.634 ($p < 0.001$).

and Mersey criteria (table 3), but very similar if the moderate and severe disability groups were combined (table 4). This would also be more consistent with the WHO definition of disability,[14] as the loss of function identified in the moderate and severe groups would be considerable, for example, non-ambulant cerebral palsy. Using the same reasoning, the impairment without disability and minor impairment groups of the Northern criteria were combined to form a single impairment outcome group.

To assess the agreement between these modified criteria, cross tabulations were performed (tables 5, 6, and 7). A total of 21 children were classified as severely disabled by all four of the outcome criteria. In addition, one child who required nasogastric tube feeding was classified as severely disabled using the Health Status Questionnaire but not by the other criteria. Two children with low developmental quotients met the criteria for impairment without severe disability using the Health Status Questionnaire, but severe disability using the Northern and Victorian criteria. Similarly, using the Health Status criteria, 215 cases were normal compared with 235–246 cases using the other methods. Discordance in these cases was mainly a result of the identification of children with mild communication difficulties or conductive hearing loss, thus meeting the Health Status criteria for impairment without severe disability but described as normal by the other methods (table 8).

Table 6 Concordance between Health Status and Victorian criteria

	Victorian criteria			
Health Status criteria	Normal	Mild	Severe	Total
Normal	213	2	–	215
Impairment	33	7	2	42
Severe	–	1	21	22
Total	246	10	23	279

κ statistic = 0.559 ($p < 0.001$).

Table 7 Concordance between Health Status and Mersey criteria

	Mersey criteria			
Health Status criteria	Normal	Mild	Severe	Total
Normal	215	–	–	215
Impairment	26	11	5	42
Severe	–	1	21	22
Total	241	12	26	279

κ statistic = 0.642 ($p < 0.001$).

The agreement between each method was measured using Cohen's kappa statistic, where a value of 1 indicates perfect agreement and a value of 0 indicates that agreement is no better than chance. Concordance between the Health Status Questionnaire and other criteria was highly significant in each case ($p < 0.001$), with a κ statistic ranging between 0.559 and 0.642.

The inclusion of cognitive function as a separate domain of the Health Status Questionnaire requires a standardised assessment (Griffiths Test or Bayley Scales) to be performed, so that a test score (expressed as a standard deviation) could be included in the analysis. However, because of the time and cost implications of such assessments, their inclusion contradicts the main purpose of the questionnaire as a simple and quick method of assessment. Therefore cognitive function was excluded from the initial analysis. Further analysis, which included the results of the Griffiths Test as a measure of cognitive function, resulted in only one child being reclassified from the impairment without disability to the severe disability group.

DISCUSSION

As published in recent studies, the survival rate for high risk infants continues to improve[1 2]; it has also been suggested that the prevalence of neurological morbidity in survivors is falling.[7] However, we have shown that the identification of disabled and impaired survivors is far from straightforward. Methodological differences between

Table 8 Areas of discordance: cases meeting the Health Status criteria for "impairment without severe disability" but "normal" by other methods

Health Status clinical domain	Northern (n=25)	Victorian (n=33)	Mersey (n=26)
Communication	18	23	19
Hearing	2	6	3
Malformation	3	3	3
Vision	1	4	1
Neuromotor	2	2	–
Physical	1	2	2

studies makes comparisons virtually impossible. Problems include sample size, cohort definition, selection bias, timing and methods of assessment, and variations in outcome criteria, particularly the definitions for disability and impairment.

In our analysis we have attempted to make logical comparisons between the results obtained when various outcome criteria are applied to the same cohort. The proportion of cases identified as having a severe disability was high when the Health Status criteria were used in their original form. This was largely a result of the inclusion of criteria for other physical difficulties such as respiratory problems and growth in the questionnaire. When the growth domain was excluded, the results were more comparable with those obtained using the other criteria. Fourteen cases were classified as severely disabled, purely on the basis of poor growth (height or weight >3 SD below the mean). This indicates the need for a consensus regarding the inclusion of growth in measures of disability.

Reclassification of the Northern, Victorian, and Mersey criteria allowed direct comparison of the methods used to measure outcome. Following these changes the concordance between the Health Status Questionnaire and the other methods was good, particularly in identifying those children with a severe disability. Discordance was the result of minor differences in the definitions such as the inclusion of feeding difficulties in the Health Status criteria. Similarly there was good concordance in identifying "normal" survivors, but overall, the Health Status Questionnaire consistently classified fewer cases as normal compared to the other methods. This was largely a result of the inclusion of children with mild delay in communication skills, for example, single words only/vocabulary >10 words in the impairment group. These cases would be likely to have low normal hearing and speech subquotients on Griffiths testing or a mildly abnormal score which would be compensated by good performance in other subscales. This would result in an overall DQ within the normal range, leading to a normal classification by methods utilising DQ scores as part of the assessment.

Previous studies have classified survivors into three or four outcome groups based on the presence and severity of cerebral palsy, impairment of hearing and vision, and the results of formal neurodevelopmental test scores.[5–9] Established tests such as the Griffiths Test and Bayley Scales give reliable results, but are time consuming and require formal training. This has been a major determinant precluding the introduction of routine surveillance programmes for all high risk infants. There is a clear need for a rapid yet accurate method of assessment, requiring minimal training but which gives reliable and comparable results when used by a range of health professionals. Additionally, the method should provide a global assessment of outcome in terms of functional impairment and not be confined to neurodevelopmental measures. The Health Status Questionnaire fulfils these criteria, taking less than 20 minutes to complete, requiring no formal training and, as we have shown, producing comparable results to established assessment methods.

The broadening of the criteria for disability with the inclusion of areas such as growth and respiratory problems in the Health Status assessment is a significant departure from established methods that rely mainly on neuromotor and cognitive outcomes. The shift of emphasis to a "loss of function" approach is more relevant in terms of assessing the impact of impairments on quality of life. Those more interested in the aetiology of disabling conditions may prefer the more traditional approach of reporting outcomes according to diagnosis (for example, cerebral palsy) but the impact of such conditions on everyday life can vary greatly between individuals. Conversely, some children may have significant impairments which affect daily living but do not fit into any particular diagnostic group.

One possible drawback of the questionnaire in its present form is the inclusion of cognition as one of the clinical domains, because this requires the completion of a formal developmental test. For this reason we excluded cognition (developmental quotient) from the initial analysis; it is clear from further analysis that its inclusion is unnecessary in that it adds little to the final classification. There may also be a case for revising some of the criteria for impairment without severe disability, for example, in the communication domain in which many children who had no difficulties in other domains were classified as having an impairment. However, the identification of mild developmental impairments at an early stage may be important so that additional support or intervention may be instituted.

Conclusion

The Health Status Questionnaire has good concordance with established criteria for disability, only if growth is considered separately and simple modifications are made to the classification of severe disability. It has significant advantages over existing methods in that it requires no formal training and is simple and quick to perform in practice. The inclusion of the "cognitive function" domain does not contribute to its utility in identifying children with a severe disability at 2 years. Given that neurodevelopmental outcome is now regarded as an essential outcome measure in most intervention studies in the neonatal population, the wider use of the Health Status Questionnaire in its modified form should be encouraged.

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