QUALITY OF LIFE OF SURVIVORS FOLLOWING TREATMENT IN THE EARLY NEONATAL PERIOD

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"I hereby declare that this work is a true and original research study."

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ABSTRACT

Intensive neonatal care has improved the survival rate of critically ill neonates. However there is growing concern about the long-term prospects of these survivors. The objectives of the study was to assess the quality of life of children aged 6 years, who in the early neonatal period required treatment at a special care unit. These children were compared with age matched controls who during the early neonatal period were not exposed to treatment at a special care unit. A retrospective cohort study was carried out with a study population of 413 of which 181 received treatment and 232 were not exposed. The quality of life was assessed subjectively by parents / carers of the study children using a postal questionnaire based on a multiattribute classification system. Eight domains were investigated: hearing, vision, speech, mobility, emotion, learning ability, self care, and pain. 67% of cases compared to 74% of controls had normal function in all eight domains. Chi squared analysis showed no significant difference between cases and controls on a global level of function. For individual attributes, cases had a significantly worse function in speech ($P=0.034$) and self care ($P=0.006$).

When compared to female cases, males cases had a significantly worse overall function ($P=0.004$) and poorer function in speech and learning abilities. No significant difference was observed when outcome was assessed according to gestational age at birth and birth weight. This study was able to show that survivors of treatment in the early neonatal period have a favourable quality of life and a good functional outcome indicating an overall beneficial effect.
TABLE OF CONTENTS

Acknowledgements
Abstract
Table of Contents (v)
List of Tables (viii)

Chapter 1: Introduction 1

Chapter 2: Literature Review 4

Measuring health outcome 4
Quality of life 6
Sources of quality of life ratings 8
Generic versus disease-specific quality of life measures 10
Different approaches to quality of life assessment 11
Multiattribute classification systems 11
Assessment of outcome of paediatric intensive care 15
Functional Status of Low Birth Weight Survivors 17
Effect of socio-environmental factors 22
Economical aspect 23

Chapter 3: Materials and Methods 24

Setting 24
Timing of the study 24
Subjects 24
Chapter 4: Results

Demographic information on study sample
Gender
Gestation
Birth weight
Study participants
Outcome
Effect of gender on outcome
Effect of gestational age on outcome
Effect of birth weight on outcome
Results of other areas of interest included in the questionnaire
Analysis of non-participants

Chapter 5: Discussion

Quality of life outcome
Outcome and gender
Functional status of low birth weight survivors
Self-Care
The role of the speech therapist
LIST OF TABLES

Table 1: Demographic data on the study sample

Table 2. Frequencies of attributes affected

Table 3. Frequencies (%) of levels within attributes in case group

Table 4. Frequencies (%) of levels within attributes in control group

Table 5. Percentage of children with affected attribute/s (%)

Table 6. Frequencies of levels within attributes in case children weighing < 1500 g at birth.

Table 7. Frequencies of levels within attributes in case children weighing 1500-2499g at birth.

Table 8. Frequencies of levels within attributes in case children weighing ≥ 2500g at birth.

Table 9. Frequencies of levels within attributes in control children weighing 1500-2499g at birth.

Table 10. Frequencies of levels within attributes in control children weighing ≥ 2500g at birth.

Table 11. Frequencies of levels within attributes in case children born before 37 completed weeks of pregnancy.

Table 12. Frequencies of levels within attributes in case children born after 37 completed weeks of pregnancy.

Table 13. Frequencies of levels within attributes in control children born before 37 completed weeks of pregnancy.

Table 14. Frequencies of levels within attributes in control children born after 37 completed weeks of pregnancy.

Table 15. Frequencies of levels within attributes in female case children.

Table 16. Frequencies of levels within attributes in male case children.

Table 17. Frequencies of levels within attributes in female control children.

Table 18. Frequencies of levels within attributes in male control children.
Clinicians and researchers interested in health care are increasingly focusing their attention on the measurement of health outcomes, or consequences, of care. Patient outcome is but one part of the classic triad - structure, process, outcome - defining quality of care. Outcome not only includes mortality and the prevalence of recognised complications, but also the impact on subjective patient well-being and functional status. Estimates of that impact are used to justify resource allocation for service provision, research and training. The subjective assessment of quality of life and functional status are primary concerns of patients, their families, and clinicians. Lack of well-being and poor functioning are also of policy interest because of societal costs due to loss of productivity and any associated use of the health services.

Intensive neonatal care medicine has made important contributions to the survival of critically ill neonates. However it requires expensive equipment and large numbers of specially trained staff, and a large share of hospital and community resources. The success of such intensive care is usually presented as mortality rates - perinatal, neonatal, and infant mortality rates - disregarding the quality of long term survival and functional outcome. More extremely low birth weight babies, premature infants, and neonates with complex previously fatal defects are treated by high technology care and there is growing concern for their long term prospects. Although fewer die, the length and quality of survival of patients surviving treatment in the early neonatal
period is uncertain. Accordingly, in addition to mortality rates, longitudinal assessment of morbidity change and health related quality of life have become important supplementary outcome measures.

Careful long-term follow-up is being done for babies who received neonatal intensive care or were very premature. A number of studies have been performed on the outcome of extremely low birth weight babies and demonstrate that low birth weight children are more likely than normal birth weight children to have suboptimal cognitive ability and poor visual motor function. Most studies report that approximately two thirds of low birth weight children function within the normal range. Major disabilities (cerebral palsy, mental retardation, visual and hearing problems needing special educational provision) occur in 5 - 15% of very low birth weight babies (1500g or less) and 15 - 25% of extremely low birth weight babies (999g or less). (Milner A.D. and Hull D. 1992).

This present study was aimed to assess the quality of life of a group of children aged 6 years, who required treatment at a special care unit, in the early neonatal period. Their outcome was compared with that of a control group who did not require any treatment during the same time period. Outcome was measured by scores in eight main domains - hearing, vision, speech, mobility, emotion, cognition, self-care, and pain.

The principal null hypothesis of this study was that there is no significant difference in quality of life between survivors of treatment in the neonatal period and children
who did not require treatment. The hypothesis was tested by a retrospective cohort study using a postal questionnaire.

The objectives of the study were to assess the quality of life of children born in 1990, who in the early neonatal period required treatment at a special care unit, and compare these children with age matched controls.

Analysis addressed the following questions:

i. Do children in the case group have a poorer quality of life than those in the control group?

ii. When cases and controls are compared, is a significant difference in functional ability present in all domains studied or is it limited to particular domains?

iii. What is the effect of gender, gestational age at birth, and birth weight on the quality of life outcome?
Measuring health outcome

In order to measure health outcome, a measure of health status is required, which in turn is based on a concept of health. One early formal definition of health was by the World Health Organisation (WHO) in 1946: 'health is a state of complete physical, psychological and social well being and not simply the absence of disease or infirmity'. Although this definition is too idealistic, it acknowledges a broader and more positive concept of health. Typical indices of health status in current use in the Western world tend to focus on disease, illness and a negative view of health. They include mortality rates; biochemical data; routinely collected statistics on health service use; behavioural data (e.g. smoking, alcohol use); and subjective indicators: self- or other-reported morbidity and disability.

Over the years there has been a greater emphasis on individuals' perception of their own health status. A common method of assessing outcome of care in a broader sense is in terms of people's ability to perform tasks of daily living (i.e. their functional ability). This concept leads to the use of three terms: impairment, disability, and handicap. These were defined by the World Health Organisation's International Classification of Impairments, Disabilities and Handicaps (1980) as follows:-

- an impairment is defined as any loss or abnormality of psychological, physiological, or anatomical structure or function.
- a disability is any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.

- a handicap is a disadvantage for a given individual, resulting from an impairment or a disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex, social and cultural factors) for that individual.

Important activities associated with everyday life such as walking, dressing, feeding, seeing, speaking and listening determine whether an impairment causes a disability. A disability refers strictly to the individual performance and does not take into account the social consequences of the restriction, the latter being included under handicap. A handicap is defined as minor if it interferes, but not seriously, with everyday life and does not imply extensive caretaking. For example, a child with cerebral palsy who is only able to move with help or a walking aid, or a child with mild mental retardation, who requires special education but does not interfere with normal functioning in the family or communication with other children, is considered to have a minor handicap. A major handicap interferes seriously with everyday life and it imposes a severe burden on the child, the caretakers, and society. A child needing total assistance in almost all everyday activities or only able to move in a wheelchair, or a seriously mentally retarded child not able to learn more than the simplest everyday activities, is considered as having a major handicap.

World Health Organisation definitions were used by Verloove-Vanhorick et al (1994) when examining the relationship between sex and disabilities or handicaps in
5 year old infants born at less than 32 weeks gestation. A detailed assessment was performed by three specially trained paediatricians and each child was categorised as disabled or handicapped. The prevalence of handicaps was three times greater in boys than in girls (21% vs 7% odds ratio 3.2). Adjustment for gestational age and birth weight did not change this (odds ratio 3.5). Further adjustment by including perinatal variables such as idiopathic respiratory distress syndrome did not alter the odds ratios. The male excess in handicaps was not related to lower mortality and therefore was not the result of a higher survival rate. Discriminant analysis showed no male excess in one kind of handicap in particular. No sex difference was observed in disabilities that did not cause a handicap.

**Quality of life**

One of the main objectives of the WHO European Health For All Policy is adding 'life' to years by improving the quality of life of individuals and also to add health to life by reducing morbidity and disability.

Quality of life is a broader concept than personal health status and has a number of components: functional ability, the degree and quality of social interaction, psychological well-being, somatic sensation (e.g. pain) and life satisfaction. There is no consensus over a definition of quality of life. Mendola and Pelligrini (1979) have defined quality of life as 'the individual's achievement of a satisfactory social situation within the limits of perceived physical capacity'. Patterson (1975) identified certain characteristics deemed essential to any evaluation of quality of life. These include (1) health, the prospect of cure vs. failure; (2) function, the ability to work
and the quality of performance; (3) comfort, the freedom from pain and the limitations to activity; (4) emotional response, self acceptance, anxiety about the future and social adjustment and (5) economics, the impact of costs and the earning capacity.

Bowling (1991) described quality of life as: “a concept representing individual responses to the physical, mental and social effects of illness on daily living, which influence the extent to which personal satisfaction with life circumstances can be achieved. Besides adequate physical well-being, it includes perceptions of well-being, a basic level of satisfaction and a general sense of self-worth”.

Fitzpatrick et al. (1992) examined the basic requirements of quality of life assessments. They identified six requirements: multidimensional construct, reliability, validity, sensitivity to change, appropriateness to question or use, and practical utility. Reliability is often assessed by examining internal reliability - the degree of agreement of items addressing equivocal concepts. When assessing validity it is important to check whether the measuring instrument covers the full range of relevant topics and if it is able to distinguish between patient groups considered to have different health statuses. The importance of different dimensions of quality of life varies among individuals and the instrument should reflect patients' priorities and preferences. One approach to improving the appropriateness of quality of life measures is to use instruments that let patients select the dimensions of most concern.
“Utility” and “value” scores are two types of preference measures used to estimate the desirability of the outcomes of the actual resulting health state. Utility refers to the desirability or preference that individuals have for a health state presented to them under conditions of uncertainty. The use of utility measures is based on the rationale that preference provides an appropriate metric for quantifying health-related quality of life, and that uncertainty is a fundamental component of program evaluation in the context of health care. Conversely, value scores are measures of preference under conditions of certainty. Both “values” and “utilities” may be obtained from raters, who assess in numeric terms their own subjectively defined health status or descriptions of different hypothetical health states. Such utility scores have been used in the paediatric population by Feeny et al (1992) on survivors of childhood cancer; by Torrance et al (1982) to measure utilities from parents of children among the general population, and by Sairgal et al (1994) to calculate the health-related quality of life scores of healthy states experienced by extremely low birth weight children and a reference group of children born at term. Boyle et al (1983) used utility values in the economic evaluation of neonatal intensive care of very-low-birth-weight infants.

Sources of quality of life ratings

Existing global measurement scales of health outcome, aiming to encompass the measurement of quality of life are based on an assessment carried out by the individual, family or physician. However, quality of life is a personal and individual issue and the question arises about who should measure quality of life.
The extent to which a physician or health professional can make a valid assessment of a patient’s quality of life was investigated in a series of cancer patients by Slevin et al (1988). A poor correlation was found between the QOL scores obtained by the health professionals and the patients. Furthermore there was considerable variability in results between different physicians. It was concluded that physicians could not accurately determine what the patients felt. A possible explanation is that physicians may be poor at measuring function because they are more accustomed to assessing symptoms than the emotional aspects or social impact of disease. Therefore, although an assessment by a physician is highly efficient with respect to time, this must be balanced against the risk of compromising validity and reliability, especially with respect to emotional or social functioning. However as suggested by Aaronson N.K. (1990), efforts should be directed at improving the reliability and validity of physician based assessments by introducing clear operational definitions of each scale level and by devoting sufficient attention to the training of raters.

Therefore, although other writers such as Hunt et al (1980) have found a large degree of agreement between physician and patient assessment scores, especially when dealing with specific functions such as physical mobility, today it is almost universally accepted that the patient is the most appropriate source of information on his / her quality of life. It is for this reason that attention over these last two decades has been focused primarily on developing quality of life measures based on direct patient feedback, either via interviews or questionnaires. However there are a number of situations in which the patient may be unwilling or unable (as in young
children) to provide quality of life ratings, and the role of the family / carers in the assessment of quality of life must be considered.

Blazeby et al (1995) studied the use of a proxy to estimate quality of life in patients with oesophageal cancer. When compared with physicians, the carers had a higher percentage agreement between patients’ and carers’ scores for function and symptom rating. Carers were better judges of the functional aspects that determine the patients’ quality of life, than the physician. This is not surprising when one compares the short period of time available to the physician to observe the patient, with the extended periods of time carers have to see the patient engaging in a wide range of activities and come in touch with his/her feelings. Physicians may be poor at measuring function because they are more accustomed to assessing symptoms rather than the emotional aspects or social impact of disease.

Magaziner et al (1988) investigated patient-proxy response comparability on measures of patient health and functional status. In general, the greater proxy contact or involvement with the patient (as indicated by shared residence, providing assistance, and first-order relationship), the better agreement.

Generic versus disease-specific quality of life measures

Another consideration is whether to use a generic or a disease specific instrument. Generic instruments cover a broad range of quality of life dimensions in a single instrument. They have the advantage of removing the need to select dimensions for a particular study, they can allow for the detection of unexpected effects, and can
facilitate comparisons among different disease groups. However such a broad approach may reduce responsiveness to the effects of health care. Disease specific instruments by including only relevant dimensions tend to increase patient acceptability, which in turn may increase responsiveness. Their disadvantages are the lack of comparability of results with those from other disease groups, and the possibility of missing effects in dimensions that are not included (Fletcher et al. 1992).

**Different approaches to quality of life assessment**

A global approach to quality of life assessment, may be based on a simple formulation such as “How would you rate your quality of life today” - this being extremely useful to give a general overview. More sophisticated utility ratings may be appropriate for certain tasks, such as calculating quality-adjusted life years or carrying out cost utility analysis in health policy research. In clinical research settings, more specific information is typically required. For this reason it is today widely accepted that quality of life assessments should be multidimensional in nature.

**Multiattribute classification systems**

A number of multiattribute systems have been developed to classify the health status of patients. One of the first multiattribute systems was devised by Fanshel and Bush (1970) and comprised four attributes: mobility, physical activity, social activity, and symptom problem complex. Torrance et al (1982) extended this multiattribute framework, for use in evaluating outcomes of low birthweight infants. The system was comprised of four attributes: physical function, role function, social-emotional...
function, and health problem. Each attribute had 4-8 levels of function. This system was developed to provide a means to describe, with reasonable precision, the diverse severity of single sequelae and the relevant combinations of sequelae associated with low birthweight and its treatment.

The system devised by Torrance et al (1982) was further extended for paediatric application by Cadman et al to assess health status in handicapped children. One study elicited preference judgements from 84 child and parent pairs to determine the core set of attributes considered to be most important. Cadman et al assessed the following attributes: physical activity, mobility, self-care, school performance, play, learning ability, happiness, pain or discomfort, sight, hearing, speech, use of limbs, cause of health problem, age at onset of health problem, and name of disease or disorder. The attributes consistently ranked highest in importance were then selected as the basis for the six attribute system: sensory and communication ability, happiness, self-care, pain or discomfort, learning and school ability, and physical activity ability. Two levels of functioning were defined for each attribute (Feeny et al 1992).

Feeny et al (1992) used the results of the study by Cadman et al to form the basis of a multiattribute classification system (Appendix I), devised to assess the health status of survivors of childhood cancer. They looked at seven attributes: sensation (sight, hearing and speech), mobility, emotional status, cognition, self-care, pain, and fertility. Each attribute was graded in severity of limitation from 1 to 5 for mobility, pain, and emotions; and 1 to 4 for the attributes of sensation, cognition, and self-
care. Ability to have children (fertility) was graded from 1 to 3. Attributes at level 1 imply no deficit whatsoever, and attributes at level 3, 4, or 5 signify the most severe limitation. An initial survey comparing patients on active therapy ($n=20$), and those off active therapy ($n=8$) for high-risk acute lymphoblastic leukaemia (ALL), Wilms’ tumor and neuroblastoma was carried out. Patients were assessed by a team of six clinicians, all of whom had participated in the treatment programme for those patients. Results showed that those patients on active therapy were suffering from a greater burden of morbidity and had a lower functional ability than those patients who had been off therapy for no more than a year. A second survey was conducted to test the system further. Thirteen childhood brain tumour patients, all on therapy, were classified by four clinicians. They were found to have a lower functional ability than patients with acute lymphoblastic leukaemia, Wilm’s tumour, or neuroblastoma.

The multiattribute health status classification system provides a means to classify the health status of patients at a point in time in terms of their ability to function on each set of attributes or dimensions of health status. The system focuses on functional capacity rather than performance. Generally, deficits in capability are defined by the reliance on mechanical devices or the assistance of another person.

The health status of a person, at a particular point in time, may be described by a seven-element vector ($x_1, x_2, x_3, x_4, x_5, x_6, x_7$) in which $x_i$ describes the level (1 to 3, 1 to 4, 1 to 5) for attribute $i$. Therefore the system is capable of representing a large number of unique health states.
The multiattribute classification system is intended to document the extent to which deficits in health status for each attribute inhibit or prohibit normal functioning, rather than to report the level at which an individual chooses to function, as would be reflected in a measure of performance. An additional advantage of the multiattribute health status classification system is that it may be linked to health status index scores that quantify health-related quality of life in terms of preferences. The desirability of, or preferences for, each health state can be quantified on the zero (dead) to one (perfect health) scale of health-related quality of life. A health status index score can be calculated that estimates the relative preference for each of the possible health states in the multiattribute system. Although the system was developed for use in paediatric oncology, it has been modified for use as a measure of health status in population-based health status surveys.

The multiattribute system was later used retrospectively at the Hospitals for Sick Children in London to classify the health status of the entire cohort (n=69) of survivors of high-risk Acute Lymphoblastic Leukaemia (ALL) available for long term follow up (Feeny et al 1993). High-risk ALL patients were chosen because of the presumption that they would suffer greater burdens of morbidity than standard risk ALL patients. Whilst for sensation, mobility, self-care, and pain, most of the high-risk ALL patients enjoyed normal functional capacity, 33% had a deficit in cognition and 28% had a deficit in emotion. The results of the above study were compared to those obtained from surveys on the prevalence of disability among children conducted by the Office of Population Censuses and Surveys (OPCS).
Although the categories and definitions used in the OPCS survey are not identical with those of the multiattribute system, ALL survivors suffered more morbidity than the general population in Great Britain.

Kanabar et al (1995) studied the quality of life of a group of survivors of childhood cancer who had completed treatment with megatherapy followed by autologous bone marrow rescue. A postal questionnaire based on Feeny’s multiattribute classification system was used. The quality of life was judged to be good in 96% of survivors, with 40% having no disability whatsoever and a further 33% reporting only minimal disability. Patients had least deficit in the attributes of sensation, mobility, and self-care.

Assessment of outcome of paediatric intensive care

Butt et al (1990) studied the long-term outcome of children after intensive care. The outcome of children of all age groups was evaluated 30 to 36 months after their admission to an intensive care unit. The health status of 77.4% of survivors remained equal or improved, whilst in 8.3% the health status deteriorated. Follow-up information about cognitive and motor neurologic function, cardiorespiratory function, degree of disability, place of residence, and school performance was obtained by means of a written questionnaire or direct telephone contact with the child’s specialist physician, surgeon, general practitioner, or parents. Then on the basis of this information, outcome was categorised into 5 groups: normal; functionally normal (both intellectually and physically) but requiring medication or medical supervision; mild disability but likely to lead an independent existence;
moderate disability dependent on care; and severe disability totally dependent on care. The study included 147 neonates of whom 43 (29%) died. Of the survivors, 22.2% were normal and 7.7% were functionally normal. The remaining 30% had some degree of disability - 13.5% mild, 1% moderate and 7.7% severe disability.

Gemke et al (1995) carried out a prospective study to assess the long term survival and health related quality of life of children admitted to an intensive care unit. Using the multiattribute classification system (modified slightly by excluding the fertility domain), the health status before admission and one year after discharge was recorded. Preadmission health status was assessed by a questionnaire completed during a structured interview within 48 hours following admission to the intensive care unit. One year after discharge an identical questionnaire was mailed to the parents to be able to assess the health status at that point in time. Their results showed that the health status in three quarters of the population was preserved, with the overall state of health being improved or equal to the pre-admission state in 72.6% of survivors (compared to 77.4% of survivors in the study carried out by Butt et al). In domain-specific health, the proportion improving or remaining unchanged varied from 77.9% (emotional functions) to 89.4% (mobility and pain). Major deterioration both in overall and domain specific health status was observed in only a small proportion of previously healthy patients with 8.7%, 1.4% and 1.4% having 3, 5 and 6 domains affected.
Maynemer and Rosenblatt (1995) assessed the outcome of neonatal intensive care unit survivors at 5 years of age and compared survivors with a control group selected from a well-baby nursery. The three tests used included the Wechsler Preschool and Primary Scale of Intelligence (WPPSI), the Beery-Buktenica Test of Visual-Motor Integration and the Griffiths Locomotor Subscale. A significant difference was observed between scores of neonatal intensive care unit (NICU) survivors and those of healthy infants in the WPPSI test but no significant difference was seen in the Beery Test or the Griffiths Locomotor subscale. The mean scores in high-risk subjects were lower and more variable than in the reference group. Approximately one fifth of NICU survivors had mental deficiencies, most apparent in the verbal domain. Gross motor impairments were more prevalent than visual motor difficulties.

Functional Status of Low Birth Weight Survivors

The current classification of low birth weight babies, according to the 10th revision of the International Classification of Diseases (ICD-10) (World Health Organisation, 1992) is in two groups: extremely low birth weight (ELBW) babies with a birth weight of 999g or less, and other low birth weight babies having a birth weight between 1000g - 2499g. However studies on low birth weight carried out prior to publication of ICD-10 also use previous definitions / classifications: low birth weight infants including those weighing 2.5kg or less, and very low birth weight (VLBW) infants are those weighing 1.5kg or less.
Centres throughout the world have reported an increased neonatal survival rate, particularly of VLBW infants, attributable in part to improved standards of perinatal care. The dramatic increase in survival of ELBW infants has generated substantial concern about their subsequent development and functioning, and a number of studies have been carried out to assess the outcome of these children. Long-term problems of LBW infants may include: cerebral palsy (4-10%); visual handicap (1-2%); sensorineural deafness (1-2%); minor motor dysfunction; and specific learning difficulties.

Kitchen et al (1987) examined changing outcome between ages of 2 and 5 years in survivors born between 1977 and 1981 with a birth weight of 500-999g. Outcome - motor function, sensorineural and cognition - was graded into mild, moderate and severe. Mild cerebral palsy referred to only slight interference with normal activities; those children attempting to walk with or without appliances were classified as having moderate cerebral palsy; and severe cerebral palsy was designated in those children unlikely ever to walk. Severe sensorineural impairment included deafness with hearing aids and/or bilateral blindness. Intellectual impairment was defined according to the score obtained on application of the Babley Mental Development Index (MDI) in the 2 year age group, and the Wechsler Pre-school Scales and Intelligence (WPPSI) to the 5.5 year age group.

At two years corrected age, the study children had a mean MDI of 91.1, significantly lower than the population mean of 100. However, at 5.5 years corrected age a catch up effect was observed and the ELBW children were performing in the normal range.
on intellectual assessment (as judged by the mean and SD). They no longer differed from the normal population on the WPPSI full scale, verbal scale, and performance scale. Investigators found that in the 5.5 year group, 60% were not impaired, 20% had minor neurobehavioral abnormalities, 10% had mild to moderate impairment, and 10% had severe sensorineural or intellectual impairment. The dominant pattern was either stability or improvement in category over time. By 5.5 years, 54% of children improved in diagnostic classification, 38% remained stable and in 8%, a deterioration was observed. The probability that this was a chance finding was remote (P=0.00004).

Kitchen et al also attempted to identify factors responsible for improvement over time in the psychological test scores. They showed that children with lower MDI scores and with better educated mothers were more likely to improve. Variables that did not reach statistical significance included behaviour and perinatal risk factors (gestation, birth weight, antepartum haemorrhage, presentation and mode of delivery, neonatal apnea, IPPV, duration of oxygen therapy, and Apgar scores at 1 and 5 minutes).

Saigal et al (1990) evaluated the intellectual and functional status at 5 1/4 years of age of a cohort of children born between 1980 and 1982 and who weighed 501 to 1000g at birth. Most of the mean scores were within 1SD of the McCarthy Motor Scale and in the Beery Test of Visual-Motor integration. Although children without neurologic impairments and those with an IQ > 68 had higher overall scores, they still performed poorly on scales for motor function and visual-motor integration.
Functional status was determined by the Vineland Adaptive Behaviour Scales, which is an interviewer-administered questionnaire that has been designed to measure the child's function in the following four domains: communication, daily living skills, socialisation and motor skills. Two thirds of the children were performing in the adequate range and the remainder in the moderately low to low range. They did most poorly in motor skills and best in socialisation.

In a further study Saigal et al (1991) focused on the cognitive abilities and school performance of extremely low birth weight (501-1000g) children born between 1977 and 1981 and who were 8 years of age at the time of the study. Their findings were similar to Kitchen et al (1987) in that approximately two thirds of the group were performing in the "normal" range on tests of cognition, language and academic achievement. However, when compared to control children matched for gender, age and social class, they were significantly disadvantaged on every measure tested and the Full Scale IQ of these children was 13 points lower than that of term control children. Between 8% and 12% of the ELBW group scored in the abnormal range (≤ - 2 SD) on the Wechsler IQ and subtests, compared with 1% to 2% of the control group. The motor performance and the visual-motor integration of the ELBW were also poorer.

Saigal et al (1994) used a utility equation from preference measures derived from a random sample of general population parents and based on multiattribute health status descriptions to study the health-related quality of life (HRQOL) of the extremely low birth weight (ELBW) survivors studied previously (Saigal et al 1991),
and compared them to a reference group of children born at term. A score of 0 = dead whilst a score of 1 = perfect health. Mean HRQOL scores were lower for ELBW (0.82, SD 0.21) than for the reference group (0.95, SD 0.07; P < 0.0001). The ELBW group had greater variability in HRQOL scores (p < 0.001), and whilst 50% of ELBW children had scores < 0.88, only 10% of the reference group had such scores. To put the numerical values of a utility scores of 0.82 in perspective, an example of a child with such a score was included. The child described was generally happy, had normal sensation and self-care abilities, however he had some limitation (not requiring help) in his ambulation because of mild left hemiplegia, was in a segregated special educational class, and had occasional discomfort relieved by non prescription drugs.

A study describing the mental and emotional well-being of school-age children with different birth weights was carried out by McCormick et al (1996). Maternal reports were obtained on three standardised measures of mental and emotional well-being (the Rand General Well-Being Scale, the Behaviour-Problem Index, and the Harter Scale of Child Competence). Lower birth weight children (< 2499g) did not differ on the General Well-Being Scale but differences in mean total scores were seen for the Behaviour Problem Index and the Harter Scale in all the low birth weight children. Any low birth weight child was twice as likely as a normal birth weight child to have a clinically significant score. The study also identified a number of correlates of mental and emotional well-being which included - childhood illness, maternal mental health, home environment score, and exposure to household cigarette smoking - which were responsible for a substantial proportion of the
increased risk. This last result has further implications on the health services, health promotion and social policy as they are potentially modifiable factors.

**Effect of socio-environmental factors**

Sameroff et al (1987) report that it is the accumulation of risk variables such as maternal, family and cultural factors, rather than the action of specific factors such as socio-economic status alone, that produce morbidity in a variety of domains. In fact Saigal et al (1990) in their assessment of ELBW survivors at 5 ½ years of age reported no differences in the intellectual performance of children by sex or social class. Of more importance to outcome was the level of maternal education (Kitchen et al 1987) or as reported by Mc Gauhey et al (1991) stressful life conditions and stressful life events. Stressful life conditions included family composition and income, extent of overcrowding, maternal education, and maternal self-perception of health status. Stressful life events measured the number of acute changes which required a degree of coping and adaptation: having moved, the father leaving the home, or the birth of a child.

Mc Gauhey et al (1991) assessed the influence of the social environment on seven dimensions of child health status: excessive bed days, school-loss days; restricted-activity days; maternal ranking of how the child is performing in school compared with peers; having failed a grade in school; behaviour problems, maternal perception of child health status. They examined both normal birth weight (NBW) and low birth weight (LBW) children. Although both NBW and LBW children in a high-risk school environment had poorer health outcomes than those children in
healthy social environments, it was the LBW children who fared worse. The latter were more likely to have worse outcomes when exposed to a high-risk social environment than normal birth weight children.

**Economical aspect**

Boyle et al (1983) evaluated the economic aspects of neonatal intensive care of very-low-birth-weight infants, using outcomes and costs of care before and after the introduction of a regional neonatal-intensive-care program. Neonatal intensive care increased both survival rates and costs; the impact of neonatal intensive care was less favourable for infants with birthweights between 500g and 999g in terms of a net economic loss when compared to infants with birthweights between 1000g and 1499g. Although still considered a benchmark study from a methodological standpoint, the conclusions drawn may not be clinically relevant today because the survival rates and health status of ELBW infants have changed remarkably in the last decade.
CHAPTER 3 : MATERIALS AND METHODS

Setting
The Maltese Islands have a population of 370,000 with an annual birth rate of about 5000 live births each year. The crude birth rate of 1990 was 15.1 per 1000 live births, with a total of 5368 registered live births. During 1990, 5293 live births were registered, of which 4898 occurred at St.Luke’s Hospital, an 870-bed, teaching, general hospital; 395 occurred at Gozo General Hospital and 75 live births occurred at private clinics or private homes (Demographic Review 1990).

Timing of the study
To examine the impact of treatment in the early neonatal period on development and learning capacity, studies of school age children are essential. Studies of younger children are useful but may not uncover subtle deficiencies in learning skills. However, the longer the follow up period the more out of date becomes the perinatal care received because of the rapidity of change in the techniques of intensive care.

Subjects
A retrospective cohort study was carried out on infants born between 1st January 1990 and 31st December 1990. These infants were on average 6 years of age when the study was carried out in 1996. The choice of the cohort was governed by the degree of completeness and reliability of the Special Care Baby Unit records, and the requirement of sufficient time period for the study group to have started attending school on a regular basis.
Cases (exposed group) included all those children born in 1990, who during the first seven days of life required treatment and were subsequently admitted to the Special Care Baby Unit at St. Luke's Hospital. The Special Care Baby Unit includes both intensive and special care. It is a 16 bed unit with 4 intensive cots with potential for ventilation. It is staffed by three consultants, junior staff at senior registrar and registrar level, paediatric nurses and midwives. Patients are admitted to the unit directly from Labour Ward, Nursery or other sources such as Gozo General Hospital, private clinics or home. Data on cases were obtained from the Special Care Baby Unit registers. To increase reliability of data and decrease the risk of accidental omission of cases, information obtained from a date of admission register was collated with another register listing all admissions by family name.

In order to enable the comparison of the quality of life of the survivors with those of the rest of the population a control group of children was also studied. By having a control group within the study group, problems with different definitions of quality of life and different categorising of patients were overcome. Controls (non-exposed group) included children born in 1990 but who did not require any treatment in the early neonatal period. They were selected randomly by a computer programme from official national sources. Although both cases and controls were selected from an updated list, a cross check with mortality records was carried out to exclude the selection of deceased children.
Assessment measures

The quality of life was assessed by the parents / carers of the children using a purpose designed structured questionnaire (Appendix II and III), which addressed eight modalities representative of health status - vision, hearing, speech, mobility, emotion, learning abilities, self care and pain. Each attribute was graded in severity of limitation from: 1 to 5 for hearing, vision, speech, mobility and pain; and 1 to 4 for the attributes of emotion, learning, and self-care. Attributes at level 1 implied no deficit whatsoever whilst levels 3, 4, or 5 signified the most severe limitation. The questionnaire was based on a modified version of Feeny et al's original multiattribute health status classification (Appendix I).

The most appropriate source of information relating to quality of life is the patient. As in this study the patients were young children, the second best approach was taken and proxy informants- such as parents or carers were used. Therefore in contrast with the study carried out by Feeny et al (1982) where the original multiattribute system was devised, in this study, neither the clinicians nor the nursing staff who directly looked after the patients were involved in the assessment, so that further bias was removed from the process (Slevin 1988). However bias may still exist in the proxy estimations of quality of life by the parents/carers.

Although a more objective assessment could have been carried out by the clinician, by asking the parents/carers to fill in the questionnaire the resulting assessment was more subjective. All surveys were completed in the comfort of the patient’s own home, rather than at a busy outpatient clinic where parents and children may be
waiting to be seen. Also, a busy outpatient clinic may not provide the clinician with an adequate basis for rating emotional, psychological, and social factors that may be pertinent to the child’s overall well-being.

Though limited by the number and nature of questions asked and the subjectivness of the responses, the postal questionnaire is a reproducible, inexpensive and effective means of audit. However, a disadvantage of self administered questionnaires is that they exclude individuals who cannot read or write or who may be nervous about completing a questionnaire. Although questionnaires administered by interviewers would avoid these problems, besides requiring extra resources for staff and for training to minimise inter-observer and intra-observer variability, they also compromise the validity of assessment (Slevin et al 1988).

The multiattribute health status classification system focuses on global health-related quality of life as well as specific limitations. It addresses the issue of quality of life for the child as a whole, as well as the level of function in each of the specific domains. Although many patients suffer deficits in more than one attribute, the multiattribute approach is able to take combinations of effects into account and document their severity.

However both Feeny et al’s original system and various modifications, including the one used in this study, have a number of disadvantages. They only measure quality of life at a single point in time, perhaps when the patient is free from disease. If a scoring system is reapplied to an individual after a short period, the reliability may be
over-rated because of memory effects. If longer intervals are allowed, the reliability may be under-rated because of changes in actual health status. Also they are based on self-assessed functioning of the patient and not on performance on any standard physiologic or psychological test. A further limitation is failure to adequately address the effects of a specific disease or its treatment. Specific organ damage may not be identified by a broad-based questionnaire, yet the sequelas of the illness may be highly relevant to the outcome for the individual.

In this study three major modifications were made to Feeny et al.’s system. First, sensation, which in the original system included the ability to see, hear or speak was subdivided into three separate attributes- hearing, seeing, and talking, so that the three functions could be evaluated separately. An extra level was added to distinguish those children who did have difficulty in one of these three functions but were not using some form of equipment. The term “equipment” was clarified to include: a hearing aid, glasses, and speech therapy. Also the terms blind, deaf, and mute were modified to “cannot see at all”, “cannot hear at all”, and “cannot speak at all” respectively. Second, the fertility modality was omitted as it was not relevant to ask this question in a group of young children. Third, a number of additional questions were included at the end of the questionnaire relating to:

1. The place of residence of the child (whether at home or an institution).
2. The type of school, if any, that the child attends (a main-stream school or a school for children with special needs).
3. The period of absenteeism from school due to illness.
4. Any medication taken on a regular basis.

5. The number, if any, of admissions to hospital.

The questionnaire was translated into Maltese and then back translated by another person into English to ensure validity of translation. As a result of the translation, some discrepancies were recognised and corrected. A pilot study of both English and Maltese translations of the questionnaire (Appendix II and III respectively) was carried out to check for understandability and acceptability, with a few ambiguous terms being corrected.

The questionnaire, together with a covering letter (Appendix IV and V) explaining the study and assuring strict confidentiality, was sent to the parent/s of each case and control. Both English and Maltese translations were sent, as well as a self addressed, postage paid reply envelope. A contact telephone number was included in the covering letter enabling those parents who experienced difficulty in filling the questionnaire to seek further explanation. Answering of any queries relating to the questionnaire was carried out by a single investigator for greater consistency.

After four weeks non-responders were contacted by phone and reminded of the importance of their participation in the study. An attempt was made to trace remaining non-responders by analysis of personal data on medical records of the child and his / her parents.
Further data collection

Separately from the questionnaires, information regarding the diagnosis of the condition/s requiring treatment in the early neonatal period was obtained from available SCBU registers and from individual case notes. Unfortunately birth weights were not being recorded in the SCBU registers in 1990, and data on birth weight was obtained using Labour Ward registers and individual case notes where appropriate.

All completed questionnaires, for both cases and controls, were analysed with the overall health status being expressed as the number of affected domains, regardless of the degree of dysfunction. A score of 0 reflects uncompromised overall health, 8 reflects impairment in any degree of all domains. Domain-specific health status was described as a profile reflecting functional level within each of the eight domains. The health status of the cases was then compared with that of the controls. The effect on outcome and level of performance according to gender, gestational age at birth, and birth weight were also assessed.

Data processing and statistical methods

Data were entered in a Microsoft Excel spreadsheet and analysed using the Data Analysis tools in the same software, as well as using the Epi-Info version 6 program. The case subjects and control subjects were compared with respect to their global health status as well as specific domains. Chi squared test was used to test the significance of differences found at a 5% significance level, with Fisher’s exact test being used instead when the expected values were less than 5.
CHAPTER 4: RESULTS

Demographic information on study sample

During the year 1990, a total of 320 patients were admitted to the Special Care Baby Unit, of which 218 (68%) required treatment in the early neonatal period. Up to the time that this study was carried out in 1996 there were 181 survivors, 37 of the original patients having died (17% mortality rate). Data on the gender, gestational age and birth weight is shown in Table 1.

Table 1: Demographic data on the study sample

<table>
<thead>
<tr>
<th></th>
<th>Cases</th>
<th>Controls</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Gender</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Males</td>
<td>97</td>
<td>132</td>
</tr>
<tr>
<td>Females</td>
<td>84</td>
<td>100</td>
</tr>
<tr>
<td><strong>Gestational age</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 37 wks</td>
<td>96</td>
<td>12</td>
</tr>
<tr>
<td>≥ 37 wks</td>
<td>85</td>
<td>220</td>
</tr>
<tr>
<td><strong>Birth weight</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>&lt; 1500 g</td>
<td>24</td>
<td>0</td>
</tr>
<tr>
<td>1500-2499 g</td>
<td>53</td>
<td>14</td>
</tr>
<tr>
<td>≥ 2500 g</td>
<td>87</td>
<td>202</td>
</tr>
</tbody>
</table>

* Birth weight records were available for 164 (90%) cases and 216 (93%) controls

Gender

There was a greater number of male children in both the case group (54%) and the controls (57%).
Gestation

In line with definitions adopted by the World Health Organisation, preterm infants included all those infants born at 28 completed weeks or more but less than 37 completed weeks. As expected there was a greater proportion of preterm births in the case group, with 53% of births occurring before 37 completed weeks of pregnancy, compared to only 5.5% in the control group.

Birthweight

As only 3 children in the case group had a birth weight ≤ 999g (extremely low birth weight), birth weights were divided into 3 categories: (1) < 1500g; (2) between 1500-2499g; and (3) ≥ 2500g. Birth weights of children in the case group were significantly lower than those in the control group. None of the children in the control group had a birth weight < 1500g. Babies with such a low birth weight would have required admission to the Special Care Baby Unit for subsequent treatment and monitoring. In the control group, 87% of controls weighed ≥ 2500g and only 6% weighed less than 2500 g at birth. In the case group, 48% weighed ≥ 2500g; 29% weighed between 1500-2499g; and 13% had a birth weight < 1500g.

Study participants

A total of 413 children were studied - 181 cases and 232 controls. In the case group, 34 children did not participate in the study: 1 child having left the country, 10 could not be traced and 23 did not respond to the questionnaire. In the control group, 59 children did not participate: 19 could not be traced and 40 did not respond to the questionnaire. The response rate achieved was 81.2% (n=147) for cases and
74.5% (n=173) for the control group. Questionnaires were all correctly filled except for 4 invalid entries in the case group (1 in the emotion category and 3 in the pain category), and 3 invalid entries in the control group (1 in the vision category and 2 in the pain category). All 7 invalid entries were excluded from any subsequent analysis relating to that particular category.

Outcome

The results obtained from the postal questionnaire are shown in tables 2-5. In table 2, data on the frequencies of the number of attributes affected are reported. There were less children that had no deficits in any of the eight attributes investigated in the case group compared to the control group. 96 (67.1%) of cases did not have any attribute affected, compared to 126 (74.1%) in the control group. However when using the Chi squared test, no significant difference between case and control children was observed in the global level of function of all the eight domains investigated.

Table 2. Frequencies of attributes affected

<table>
<thead>
<tr>
<th>Number of attributes affected</th>
<th>Number of cases (%)</th>
<th>Number of controls (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>0</td>
<td>96 (67.1)</td>
<td>126 (74.1)</td>
</tr>
<tr>
<td>1</td>
<td>28 (19.6)</td>
<td>31 (18.2)</td>
</tr>
<tr>
<td>2</td>
<td>7 (4.9)</td>
<td>7 (4.1)</td>
</tr>
<tr>
<td>3</td>
<td>6 (4.2)</td>
<td>4 (2.4)</td>
</tr>
<tr>
<td>4</td>
<td>3 (2.1)</td>
<td>1 (0.6)</td>
</tr>
<tr>
<td>5</td>
<td>1 (0.7)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>6</td>
<td>1 (0.7)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>7</td>
<td>1 (0.7)</td>
<td>0 (0.0)</td>
</tr>
<tr>
<td>8</td>
<td>0 (0.0)</td>
<td>1 (0.6)</td>
</tr>
<tr>
<td>Total</td>
<td>143 (100)</td>
<td>170 (100)</td>
</tr>
</tbody>
</table>

Note: 4 cases and 3 controls were excluded because of an invalid response.
Also, the children in the case group have higher scores (and hence a lower functional ability) for most attributes, when compared to controls. Data on the frequencies of levels within each attribute are reported in Table 3 for the cases and Table 4 for the controls.

Table 3. Frequencies (%) of levels within attributes in case group

<table>
<thead>
<tr>
<th>Attribute level</th>
<th>Hearing</th>
<th>Vision</th>
<th>Speech</th>
<th>Mobility</th>
<th>Emotion</th>
<th>Learning</th>
<th>Self care</th>
<th>Pain</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>145</td>
<td>137</td>
<td>131</td>
<td>137</td>
<td>142</td>
<td>124</td>
<td>135</td>
<td>130</td>
</tr>
<tr>
<td></td>
<td>(98.6)</td>
<td>(93.2)</td>
<td>(89.1)</td>
<td>(93.2)</td>
<td>(97.3)</td>
<td>(84.4)</td>
<td>(91.8)</td>
<td>(90.3)</td>
</tr>
<tr>
<td>2</td>
<td>2</td>
<td>2</td>
<td>0</td>
<td>3</td>
<td>3</td>
<td>11</td>
<td>5</td>
<td>14</td>
</tr>
<tr>
<td></td>
<td>(1.4)</td>
<td>(1.4)</td>
<td>(0.0)</td>
<td>(2.0)</td>
<td>(2.1)</td>
<td>(7.5)</td>
<td>(3.4)</td>
<td>(9.7)</td>
</tr>
<tr>
<td>3</td>
<td>0</td>
<td>8</td>
<td>5</td>
<td>4</td>
<td>1</td>
<td>11</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>(0.0)</td>
<td>(5.4)</td>
<td>(3.4)</td>
<td>(2.7)</td>
<td>(0.7)</td>
<td>(7.5)</td>
<td>(2.0)</td>
<td>(0.0)</td>
</tr>
<tr>
<td>4</td>
<td>0</td>
<td>0</td>
<td>9</td>
<td>2</td>
<td>0</td>
<td>1</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>(0.0)</td>
<td>(0.0)</td>
<td>(6.1)</td>
<td>(1.4)</td>
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<td>(0.7)</td>
<td>(2.7)</td>
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<td>5</td>
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<td>NA</td>
<td>0</td>
</tr>
<tr>
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<td>(0.0)</td>
<td>(0.0)</td>
<td>(1.4)</td>
<td>(0.7)</td>
<td></td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>147</td>
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<td>(100)</td>
<td>(100)</td>
<td>(100)</td>
<td></td>
</tr>
</tbody>
</table>

Note: NA = not applicable

1 invalid entry in the emotion category and 3 invalid entries in the pain category were excluded.

Table 4. Frequencies (%) of levels within attributes in control group

<table>
<thead>
<tr>
<th>Attribute level</th>
<th>Hearing</th>
<th>Vision</th>
<th>Speech</th>
<th>Mobility</th>
<th>Emotion</th>
<th>Learning</th>
<th>Self care</th>
<th>Pain</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>171</td>
<td>159</td>
<td>165</td>
<td>171</td>
<td>166</td>
<td>155</td>
<td>170</td>
<td>155</td>
</tr>
<tr>
<td></td>
<td>(98.8)</td>
<td>(92.4)</td>
<td>(95.4)</td>
<td>(98.8)</td>
<td>(96.0)</td>
<td>(89.6)</td>
<td>(98.3)</td>
<td>(90.6)</td>
</tr>
<tr>
<td>2</td>
<td>1</td>
<td>3</td>
<td>3</td>
<td>0</td>
<td>7</td>
<td>15</td>
<td>0</td>
<td>15</td>
</tr>
<tr>
<td></td>
<td>(0.6)</td>
<td>(1.7)</td>
<td>(1.7)</td>
<td>(0.0)</td>
<td>(4.0)</td>
<td>(8.7)</td>
<td>(0.0)</td>
<td>(8.8)</td>
</tr>
<tr>
<td>3</td>
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<td>10</td>
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<td>1</td>
<td>0</td>
<td>1</td>
</tr>
<tr>
<td></td>
<td>(0.0)</td>
<td>(3.8)</td>
<td>(1.2)</td>
<td>(0.0)</td>
<td>(0.0)</td>
<td>(0.6)</td>
<td>(0.0)</td>
<td>(0.6)</td>
</tr>
<tr>
<td>4</td>
<td>0</td>
<td>0</td>
<td>1</td>
<td>0</td>
<td>0</td>
<td>2</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>(0.0)</td>
<td>(0.0)</td>
<td>(0.6)</td>
<td>(0.0)</td>
<td>(0.0)</td>
<td>(1.2)</td>
<td>(1.7)</td>
<td>(0.0)</td>
</tr>
<tr>
<td>5</td>
<td>1</td>
<td>0</td>
<td>2</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>NA</td>
<td>0</td>
</tr>
<tr>
<td></td>
<td>(0.6)</td>
<td>(0.0)</td>
<td>(1.2)</td>
<td></td>
<td></td>
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<td>(100)</td>
<td>(100)</td>
<td>(100)</td>
<td>(100)</td>
<td></td>
</tr>
</tbody>
</table>

Note: NA = not applicable

1 invalid entry in the vision category and 2 invalid entries in the pain category were excluded.
As illustrated in Table 5, the case group compares very well with the control group, especially for hearing, vision, emotion, and pain. In the four remaining attributes—speech, mobility, learning, and self-care, the number of children enjoying normal functional capacity in the control group is on average 5% higher than in the case group.

Table 5. *Percentage of children with affected attribute/s (%)*

<table>
<thead>
<tr>
<th>Study group</th>
<th>Hearing</th>
<th>Vision</th>
<th>Speech</th>
<th>Mobility</th>
<th>Emotion</th>
<th>Learning</th>
<th>Self-care</th>
<th>Pain</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cases</td>
<td>1.4</td>
<td>6.8</td>
<td>10.9</td>
<td>6.8</td>
<td>2.8</td>
<td>15.7</td>
<td>8.1</td>
<td>9.7</td>
</tr>
<tr>
<td>Controls</td>
<td>1.2</td>
<td>7.5</td>
<td>4.7</td>
<td>1.2</td>
<td>4.0</td>
<td>10.5</td>
<td>1.7</td>
<td>9.4</td>
</tr>
</tbody>
</table>

Using the Chi squared test, a significant difference was found only in two attributes—speech and self-care. For speech, 10.9% of cases reported reduced function compared to 4.7% in the controls (P=0.034). For self-care, 8.1% of cases had a deficit, compared to 1.7% of controls (P=0.006). Detailed tabulated results by gender, gestational age, and birth weight are shown in tables 6-18 (Appendix VI).

**Effect of gender on outcome**

When comparing the outcome of male and female children in the case group using the Chi squared test, a statistically significant difference in their overall performance was observed (P = 0.004). Boys had a lower overall performance in the eight domains assessed with 45 (60.0%) having normal function in all domains and 34 (40%) having a deficit in one or more domains. In comparison, 51 (80%) of female
children in the case group reported normal function in all domains and only 13 (20%) reported a limitation in the level of function in one or more domains. No statistically significance was seen when the outcome of male controls was compared to that of female controls. Comparison of children of the same sex in the two groups (cases and controls) showed a significant difference in males ($P = 0.01$) but not in females. 68 (75%) of male control children had normal function in all attributes (compared to 60%) in male case children.

Where a statistically significant difference was found, further analysis was performed to determine whether all or specific domains were affected. The Student t-test was used to compare mean scores obtained for each domain. When male and female case children were compared, a significant functional difference was seen in only two domains - speech and learning abilities. In the speech domain, the mean scores were 1.5 for boys and 1.1 for girls ($P = 0.05$). The mean score for learning ability was 1.4 in boys and 1.1 in girls ($P = 0.001$). Comparison of male children in the case group with males in the control group, also showed a significant difference in speech and in learning ability. For the speech domain the mean scores were 1.5 in male cases compared to 1.1 in controls ($P = 0.01$). For learning ability, male cases had a mean score of 1.4, whilst male controls had a mean score of 1.1 ($P = 0.01$).

**Effect of gestational age on outcome**

No statistical significant difference was found when comparing the outcomes of preterm and term children in both case and control groups. Comparison of
performance in preterm cases to that in preterm controls, as well as that of term cases compared to term controls, did not show any significantly difference.

Effect of birthweight on outcome
The outcome of both case and control children in the same birthweight category was analysed. There was no significant difference in the level of performance when comparing case children with control children of the same birthweight category. As there were no children weighing <1500g in the control group, the outcome of case children with a birthweight < 1500g was compared with that of cases children who weighed ≥ 2500g at birth. The results showed no statistically significant differences.

Results of other areas of interest included in the questionnaire
All children in the case group lived at home, as did all the children in the control group except for one child suffering from DiGeorge syndrome. This child had a poor quality of life with abnormal function in seven of the domains investigated. He is very dependent on his carers as can be seen from his scores: level 4 in self care and level 5 in speech and mobility.

All of the case group children attended ordinary school except for one child who attended a school for children with special needs. In the control group, 2 attended a special school, 1 child (referred to above as suffering from DiGeorge syndrome) did not attend school at all, and the rest attended a normal school. School-loss days was included as a measure of restricted activity due to illness. School attendance in case children was not very different from that of controls. Only 3.4% of cases and 2.9%
of controls were absent from school due to illness for more than four weeks per scholastic year. None missed more than three months.

10.2% of children in the case group and 6.9% of control children were taking medication on a regular basis. However most parents failed to write the exact name of medication taken. When analysing the number of admissions to hospital only 6 case children and 3 control children had more than 5 admissions.

Analysis of non-participants

The response rate achieved in the study was 81% for cases and 74.5% for the control group. The slightly lower response rate in the control group could be accounted for by the fact that less detailed birth records were available for children in the control group. As these on average only spent about 48 hours in the nursery at the time of birth, case notes did not include a contact telephone number of immediate family and there was no way of tracing and contacting some of these children.

With respect to their birth weight and gestational age at birth, non-responders in both case and control groups did not appear to be markedly different from participants in their respective group. Regarding the possible outcome of those children who could not be traced, the fact that there seems to be no trace of these children in the hospital records or any history of recent admission to hospital or attendance at the Child Development Assessment Unit, is more suggestive of a good quality of life, rather than a poor one.
CHAPTER 5: DISCUSSION

The health and well-being of children and young people are important to a country’s health policy. Improvement in the health of today’s children may be regarded as an investment in the future society. The World Health Organisation (WHO) in its health policy for Europe also acknowledges the importance of child health. Target 7 of the WHO Health for all targets for the year 2000 is to improve the health of all children and young people giving them the opportunity to grow and develop to their full physical, mental and social potential.

Greater medical knowledge and better technology mean that more children survive various problems at birth and neonatal period, such as premature birth, congenital malformations, and perinatal hypoxia. Their survival may not always be free of disability and handicap. Identification of the overall quality of life and any limitations in basic functions, is important for policy and planning. One of the strategies put forward by WHO that may be implemented to achieve the health for all target is to ensure social, economic, and psychological support for disadvantaged children (including those with long-term illness and disability), and for their families. Such a strategy requires the setting up of appropriate intersectoral mechanisms involving the health, education, social security, employment and finance sectors.

Questions are often raised by governmental sources, health care providers, parents, and members of society about the quality of life of survivors of neonatal care. A
major concern is whether after requiring extensive invasive and expensive neonatal care, many of these infants go on to spend a lifetime in a severely disabled state, considered by some as worse than dying at birth.

Recent developments in intensive neonatal care have increased survival rates and this has led to concern with the quality of life of survivors. The success of intensive neonatal care should not only be focused on the measurement of quantitative survival alone, and attention must be paid to the quality of life experienced by survivors. While numerous studies have addressed the impact of morbidity and mortality of various conditions associated with neonatal intensive care, few have focused on the quality of life issue and the overall long-term well-being of survivors.

The large reduction in perinatal mortality over the past 20 years is due mainly to better antenatal care, improved management of labour and to the development of skilled intensive care for sick babies. Although they only amount to about 1% of all births, these babies take up a relatively large amount of available skilled medical and nursing resources.

Babies requiring treatment in the early neonatal period include the following categories:
- preterm babies and babies of low birth weight (many under 1500 g or less than 34 weeks gestation).
- respiratory disorders including pre-term babies with severe respiratory distress syndrome; severe pneumonia; meconium aspiration; pneumothorax; infants with prolonged apnoeic attacks.
- cerebral disorders including severe and persistent fits; severe cerebral traumatic, ischaemic or hypoxic injury.
- certain infections including septic screening for meningitis or septicaemia.
- congenital abnormalities e.g.: congenital heart disease, oesophageal atresia, neural tube defects, diaphragmatic hernia, etc.

Quality of life outcome

The data obtained from this study allows one to form a global picture of the quality of life and functional ability of survivors of treatment in the early neonatal period, who are now 6 years of age. The results from this study suggest that the quality of life after treatment in the early neonatal period, as judged by the parents / carers, is good: 67% had normal overall health, 20% had one domain affected and 13% had two or more domains affected. When compared to age matched controls, no statistically significant difference in the overall functional status was observed.

The results obtained also compare favourably with those of other similar studies. Feeny et al (1992) assessed the survivors of childhood ALL and found that overall health was normal in 42%, one domain was affected in 32%, and 26% had 2 or more domains affected. When analysing the outcome of children at 2 ½ to 3 years after neonatal intensive care, Butt et al (1990) reported normal function in 77.7%, the rest have mild (13.5 %), moderate (1%) or severe (7.7%) disability. Outcome was
also evaluated according to 5 admission categories: hyaline membrane disease, prematurity, asphyxia, oesophageal atresia and others. Those neonates admitted with hyaline membrane disease (n=37) had a very favourable outcome with 31 (83.8%) having normal function, 2 (5.4%) mild handicap, 1 (2.7%) moderate handicap and 3 (8.1%) severe handicap. From a total of 18 preterm infants survivors, 14 (77.8%) had normal function whilst 4 (22.2%) had mild handicap. The worst outcome was seen in those with neonatal asphyxia, 10 (out of a total of 21) survived with only 4 (40%) having normal function, 1 (10%) had mild handicap and 5 (60%) had severe handicap. Unfortunately assessment of outcome according to the condition requiring treatment, was not possible in this study due to lack of exact diagnosis in a large proportion of the case group.

Comparison of case children, who received treatment in the early neonatal period, with control children yielded a statistically significant difference in only two of the eight attributes investigated. These were speech and self-care. A significant limitation in speech was also found by Mayemer and Rosenblatt (1995) in their assessment of neonatal intensive unit survivors (NICU). They reported that approximately one fifth of survivors had mental deficiencies, most apparent in the verbal domain. Gross motor impairments were more prevalent than visual motor difficulties.

**Outcome and gender**

In this study, assessment of functional outcome according to gender showed that boys in the case group had a significantly poorer overall function than female case children, with speech and learning abilities being affected as specific domains.
Verloove-Vanhorick et al (1994) examined the relationship between sex and disabilities or handicaps at 5 years of age in infants born at less than 32 weeks gestation. The prevalence of handicaps was three times greater in boys than in girls. Adjustment for gestational age, birth weight, and even perinatal variables such as idiopathic distress syndrome did not appreciably alter the above ratio. The male excess in handicaps was not related to lower mortality, and therefore was not a mere consequence of a higher survival rate.

Functional status of low birth weight survivors

In their studies, both Saigal et al (1990 and 1991) and Kitchen et al (1987) reported that approximately two thirds of ELBW children were performing in the “normal” range in tests of cognition, language and academic achievement. However when compared to a control group of children, they were significantly disadvantaged on every measure tested, and did most poorly on scales for motor function and visual-motor integration. Mean HRQOL scores were lower for ELBW (0.82, SD 0.21) than for the reference group (0.95, SD 0.07; P < 0.0001). Saigal et al (1991) also reported approximately one fourth of the ELBW children were wearing prescription glasses.

In this study no significant difference was observed when cases and controls were analysed by gestation or birth weight. However the number of children with low birth weights was extremely small with only 3 cases weighing < 999g and no control children weighing < 1500g.
Additional questions were added at the end of the questionnaire to obtain further insight into the quality of life of the study group and examine any policy implications. All children in the case group, and all but one of the control children, live at home rather than an institution. This is a very positive and encouraging finding, although one cannot exclude the possibility that as some of the children with a moderate amount of functional limitation grow older, their ageing parents/carers may no longer be able to cope any more and may turn to institutional care as an alternative.

**Self care**

The development of normal social and self-help skills, like eating, washing, toileting, is important for the child to become as less dependent on others as possible. Therapists have a major task in promoting these developmental skills and include both physiotherapists and occupational therapists. Therapists work directly with children and the relationship between the child and the therapist is an important determinant of progress. There are also a number of aids that help with skills.

**Role of the speech therapist**

The specialised speech therapist is essential to the team assessment of the child and in directing therapy. They must be involved early and not just as an afterthought because speech has failed to develop. The speech therapist has a number of roles, the first begins very early in the child’s life. In their initial assessment they evaluate tongue, palate and mouth movements and advise over feeding problems. At a slightly later age they can assess the child’s inner language, the essential prerequisite
to expressive language. They will see what concepts of language have developed and how this development can be enhanced through play. The therapist will not be confined to verbal communication but will concentrate on functional communication by all means so that the child’s needs can be met. In the pre-school years the therapist works with and through the parents and carers of the child (e.g.: nursery nurses in a day nursery). As in physical development, the development of communication may not be automatic. Often a considerable amount of therapy through play is necessary. Hence it is doubly important that parents and carers understand concepts of early language development and enact the development programmes themselves. Once at school the child’s communication therapy is again more likely to be directed by the speech therapist via the work of teachers and parents than given directly. The therapist will advise on alternative communication systems.

**Education and type of school**

In the UK, the Warnock Committee report (Special Education Needs, 1978) reviewed the current position for children with learning difficulties and made new recommendations concerning their management. A new concept was introduced - namely that provision should be made according to the educational needs of the child, rather than the category of disability. A positive look at the child’s strengths, rather than his deficits is emphasised. In Malta these recommendations have been adopted by both the education department and health professionals.
The type of school attended depends on the level of disability of the child, the learning ability of the child, the special resources that are needed, the geography of the school building which should permit easy access for the child with limited mobility, the wishes of the child and parents and the attitude of the health authority, education authority and the individual school. However the modern trend (following recommendation by the Warnock Committee) is that children should be educated in ordinary schools as far as is reasonably practical. This gives the children a wider choice of curriculum as well as a greater opportunity for normal social contacts, avoiding the isolation that has been experienced by many handicapped children in the past.

Integration of children with limitation of function in one or more domains, into ordinary schools can be seen for the children in this study. Only one child in the case group attended a special school. Teacher reports in study by Saigal et al (1990) suggest that one fifth of the ELBW children were already receiving special assistance in school at the age of 5 years. However the term “special assistance” was not defined. Results obtained from this study show that 7.5% of children in the case group and 1.2% of children in the control group required special educational assistance (such as a facilitator). Education in mainstream schools presupposes the provision of interpreter and other appropriate support services. Adequate accessibility and support services, designed to meet the needs of persons with different disabilities must be provided.
Progress at school

Only parents of one child attending an ordinary school reported that their child was making very poor progress. In fact following assessment by a multidisciplinary team, a decision was taken that the child would obtain greater benefit if educated in a special school. Progress at school and the type of curriculum provided depends not only upon the intellectual level but on the presence or absence of other handicaps. Thus the school may need to provide physiotherapy, occupational therapy, speech therapy, the teaching of a sign system for those with severe communication difficulties, or a behaviour modification programme for those whose behaviour problems prevent effective learning. Records of the child’s progress are valuable in showing parents the new skills that the child is acquiring. Parents need to be constantly reassured that the children do learn, even if at a slower pace and with far more repetition than in an ordinary school. Small classes, a high number of staff to the number of children and their training in special education, ensure optimal progress.

Other variables

Many adverse factors in the perinatal period and later childhood influence eventual neurological and psychological status. Learning abilities are influenced by a wide range of factors such as family history, social and environmental factors, vision and hearing defects, mild mental handicap, medication, such as the use of antihistamines which are still frequently used for hay fever and anti-convulsants which may make the child drowsy or ataxic, frequent school absence and poor attention control.
A limitation of this study is that the effect of social class was not investigated. No social classification system has yet been devised specifically for the Maltese population. Furthermore, studies focus on the effect of a number of factors in the social environment rather than on just social class grouping. Kitchen et al (1987) identified various factors responsible for improvement in psychologic test scores and they showed that improvement was more dependent on maternal education rather than perinatal factors such as gestation or birth weight, whilst Mc Gauhey et al (1991) outlined the role of stressful life conditions and stressful life events. Sameroff et al (1987) report that it is the accumulation of risk variables such as maternal, family and cultural factors, rather than the action of specific factors such as socio-economic status alone, that produce morbidity in a variety of domains. In fact Saigal et al (1990) in their assessment of ELBW survivors at 5½ years of age reported no differences in the intellectual performance of children by sex or social class.

Further studies

It would be interesting to carry out a follow up study of these children at a later stage, such as ten years of age, to examine any changes in quality of life and very importantly, to see how they are coping with more advanced schoolwork and assess their learning abilities at this stage. A prospective study could be carried out, and the effect of other possible variables such as: the condition requiring treatment; duration of treatment and stay in the neonatal care unit; requirement of mechanical ventilation; social class; and maternal education could be assessed.
This study has also identified the need and the value of follow-up of other cohorts of children who received care in the neonatal period. Knowledge on the long-term functional outcome and quality of life of these children is important to clinicians as a measure of the effectiveness of treatment, and to all health professionals in the provision of any required services. It also provides a brighter picture for parents of neonates requiring treatment. The level of well-being and functional status of this increasing group of survivors has further implications on the type and effectivity of ongoing support services, social and economic policy.

Conclusion

This study was able to show that although a significant difference in speech and mobility was found between children in the case group and those in the control group, the overall quality of life was much better than is often assumed or feared. Another important factor to consider is that without intensive care a large proportion of the cases would not have survived. It is very encouraging that 67% of children in the case group compared to 74% of those in the control group were functioning in the normal range and none of the domain investigated - hearing, vision, speech, mobility, emotion, learning, self-care and pain - were affected. Therefore, few additional community and educational resources will be utilised.

In conclusion, the writer found that survivors of treatment in the early neonatal period have a favourable quality of life and a good functional outcome, indicating an overall beneficial effect. Very few survivors had a poor functional outcome, with
67% having no functional limitations in any of the eight domains assessed. My findings support the continued investment of resources in neonatal care.
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Appendix I

Multiattribute health status classification system

<table>
<thead>
<tr>
<th>Attribute</th>
<th>Level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Sensation</td>
<td>1</td>
<td>Ability to see, hear, and speak normally.</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Requires equipment to see or hear or speak.</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Sees, hears, or speaks with limitations even with equipment.</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Blind, deaf, or mute.</td>
</tr>
<tr>
<td>Mobility</td>
<td>1</td>
<td>Ability to walk, bend, lift, jump, and run normally for age.</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Walks, bends, lifts, jumps, or runs with some limitations but does not require help.</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Requires mechanical equipment (such as canes, crutches, braces, or wheelchair) to walk or get around independently.</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Requires the help of another person to walk or get around and requires mechanical equipment as well.</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>Unable to control or use arms and legs.</td>
</tr>
<tr>
<td>Emotion</td>
<td>1</td>
<td>Generally happy and free from worry</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Occasionally fretful, angry, irritable, anxious, depressed, or suffering ‘night terrors’.</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Often fretful, angry, irritable, anxious, depressed, or suffering ‘night terrors’.</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Almost always fretful, angry, irritable, anxious, or depressed.</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>Extremely fretful, angry, irritable, or depressed, usually requiring hospital admission or psychiatric institutional care.</td>
</tr>
<tr>
<td>Cognition</td>
<td>1</td>
<td>Learns and remembers schoolwork normally for age.</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Learns and remembers schoolwork more slowly than classmates as judged by parents and / or teachers.</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Learns and remembers very slowly and usually requires special educational assistance.</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Unable to learn and remember.</td>
</tr>
<tr>
<td>Self-care</td>
<td>1</td>
<td>Eats, bathes, dresses, and uses the toilet normally for age.</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Eats, bathes, dresses, or uses the toilet independently but with difficulty.</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Requires mechanical equipment to eat, bathe, dress, or use the toilet independently.</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Requires the help of another person to eat, bathe, dress, or use the toilet.</td>
</tr>
<tr>
<td>Pain</td>
<td>1</td>
<td>Free of pain and discomfort</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Occasional pain. Discomfort relieved by non-prescription drugs or self-control activity without disruption of normal activities.</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Frequent pain. Discomfort relieved by oral medicines with the occasional disruption of normal activities.</td>
</tr>
<tr>
<td></td>
<td>4</td>
<td>Frequent pain; frequent disruption of normal activities. Discomfort requires prescription narcotics for relief.</td>
</tr>
<tr>
<td></td>
<td>5</td>
<td>Severe pain. Pain not relieved by drugs and constantly disrupts normal activities.</td>
</tr>
<tr>
<td>Fertility</td>
<td>1</td>
<td>Ability to have children with a fertile spouse.</td>
</tr>
<tr>
<td></td>
<td>2</td>
<td>Difficulty in having children with a fertile spouse.</td>
</tr>
<tr>
<td></td>
<td>3</td>
<td>Unable to have children with a fertile spouse.</td>
</tr>
</tbody>
</table>
Appendix II

QUESTIONNAIRE

Please circle the appropriate number which corresponds with your child’s health at present.

HEARING

1. My child is able to hear normally for his / her own age.
2. My child seems not able to hear normally for his / her own age.
4. My child has difficulty hearing even with a hearing aid.
5. My child cannot hear at all.

SEEING

1. My child is able to see normally for his / her own age.
2. My child does not see well but does not wear glasses.
3. My child uses glasses to see well.
4. My child has difficulty seeing even with glasses.
5. My child cannot see at all.

SPEECH

1. My child is able to speak normally for his / her own age.
2. My child has some difficulty in speaking but has never been to a speech therapist.
3. My child has required speech therapy to speak normally.
4. My child has difficulty speaking even after speech therapy.
5. My child cannot speak at all.

MOBILITY

1. My child is able to walk and run about normally for his / her own age.
2. My child is able to walk and run slower than other children of his / her own age, but does not require help from others.
3. My child requires mechanical equipment (such as a walking stick, crutches or a wheelchair) to move around.
4. My child requires the help of another person to walk and move around, as well as the mechanical equipment.
5. My child is unable to control or use his / her arms or legs.
EMOTION

1. My child is generally happy and sociable.
2. My child is often irritable, angry, anxious or depressed.
3. My child is almost always fretful, irritable, angry, anxious or depressed.
4. My child is extremely fretful, irritable, angry or depressed and usually requires psychiatric care.

LEARNING ABILITIES

1. My child is able to remember and learn his / her schoolwork normally for his / her own age.
2. My child is able to learn and remember his / her schoolwork more slowly than other children in his / her class as judged by yourselves and / or teachers.
3. My child learns and remembers very slowly and usually requires special educational assistance (such as a facilitator).
4. My child is unable to learn and remember at all.

SELF CARE

1. My child is able to eat, drink, bathe, dress, and use the toilet normally for his / her own age.
2. My child is able to eat, drink, bathe, dress, and use the toilet by himself / her self but with difficulty.
3. My child requires mechanical equipment (special knives and forks, lifting gear etc.) to eat, drink, bathe, dress, and use the toilet on his / her own.
4. My child requires the help of another person to eat, drink, bathe, dress, or use the toilet.
PAIN

1. My child is almost always free of pain and discomfort.
2. My child is sometimes in pain but this does not stop him / her from doing things (e.g. going to school, playing.)
3. My child is frequently in pain for which he / she needs pain killers (give name of medication: )
   and it does sometimes stop him / her from doing things.
4. My child is frequently in pain for which he / she needs pain killers (give name of medication: )
   and it stops him / her from doing things a lot of the time.
5. My child is in severe pain and this is not often relieved by the drugs he / she takes (give name of medication: )
   and it stops him / her from doing things all the time.

Other areas of interest

1. Does your child live at :
   (a) home
   (b) an institution

2. What type of school does your child attend ?
   (a) a normal school
   (b) a school for children with special needs
   (c) does not attend school

3. How often is your child absent from school due to any illness ?
   (a) less than 4 weeks / year
   (b) between 4 - 12 weeks / year
   (c) more than 3 months / year

4. Is your child taking any medication on a regular basis ?
   (a) yes - (write name of medication )
   (b) no

5. Has your child ever been admitted to hospital ?
   (a) no
   (b) yes How many times ?
Appendix III

KWESTJONARJU

Jekk joghqbok immarka b’cirku fuq in-numru li jaqbel mas-sahha ta’ ibnek / bintek ____________________________ illum.

SMIGH

1. Ibni (binti) kapaci jisma b’mod normali ghall-eta tieghu.
2. Ibni (binti) jidher li ma jismax b’mod normali ghall-eta tieghu.
3. Ibni (binti) juza apparat tas-smigh biex jisma b’mod normali.
4. Ibni (binti) isibha diffic1i biex jisma’ avolja juza apparat tas-smigh.
5. Ibni (binti) ma jista jisma xejn.

IL-VISTA

1. Ibni (binti) kapaci jisma b’mod normali ghall-eta tieghu.
2. Ibni (binti) jidher li ma jismax b’mod normali ghall-eta tieghu.
3. Ibni (binti) juza apparat tas-smigh biex jisma b’mod normali.
4. Ibni (binti) isibha diffic1i biex jisma’ avolja juza apparat tas-smigh.
5. Ibni (binti) ma jista jisma xejn.

IT-TAHDIT

1. Ibni (binti) kapaci jisma b’mod normali ghall-eta tieghu.
2. Ibni (binti) jidher li ma jismax b’mod normali ghall-eta tieghu.
3. Ibni (binti) juza apparat tas-smigh biex jisma b’mod normali.
4. Ibni (binti) isibha diffic1i biex jisma’ avolja juza apparat tas-smigh.
5. Ibni (binti) ma jista jisma xejn.

MIXI

1. Ibni (binti) kapaci jimxi u jigri b’mod normali ghall-eta tieghu.
2. Ibni (binti) kapaci jimxi u jigri b’mod normali ghall-eta tieghu, imma ma jehtieg l-ghajnuna ta’ xi persuna ohra.
3. Ibni (binti) jehtieg apparat mekkankanu (bhal bastun, krozzi jew siggu tarroti) biex jimxi.
4. Ibni (binti) jehtieg l-ghajnuna ta’ xi persuna ohra biex jimxi, kif ukoll apparat mekkankanu.
5. Ibni (binti) mhux kapaci jikkontrolla jew juza dirghajh jew saqajh.
EMOZZJONI

1. Ibni (binti) huwa generalment kuntent u socjevoli.
2. Ibni (binti) huwa ta’ sikwit bin-nervi, irrabjat, anzjuz jew imdejjaq.
3. Ibni (binti) kwazi dejjem jinghi jew ikun bin-nervi, irrabjat, anzjuz jew imdejjaq.
4. Ibni (binti) jinghi hafna, jkun bin-nervi, irrabjat jew imdejjaq u generalment jehtieg kura psikiatrika.

ABILITA GHAT-TAGHLIM

1. Ibni (binti) kapaci jiftakar u jitghallem ix-xoghol ta’ l-iskola bhal tfal ohra tal-klassi tieghu.
2. Ibni (binti) kapaci jiftakar ix-xoghol ta’ l-iskola iktar bil-mod minn tfal ohra tal-klassi tieghu, skond il-fehma tal-genituri u / jew l-ghalliema.
3. Ibni (binti) jitghallem u jiftakar bil-mod hafna u generalment jehtieg ghajnuna edukattiva specjali ( bhal : ‘facilitator’ ; jew imur Skola Specjali ).
4. Ibni (binti) mhux kapaci jitghallem u ma jiftakar xejn.

KURA PERSONALI

1. Ibni (binti) kapaci jiekol, jixrob, jinhasel, jilbes, u juza t-‘toilet’ b`mod normali skond l-eta tieghu.
2. Ibni (binti) kapaci jiekol, jixrob, jinhasel, jilbes, u juza t-‘toilet’ wahdu, imma b` difficulta.
3. Ibni (binti) jehtieg apparat mekkaniku ( bhal: frieket u skieken speciali ; jew ‘lift’ ) biex jiekol, jixrob, jinhasel, jilbes, jew juza t-‘toilet’ wahdu.
4. Ibni (binti) jehtieg l-ghajnuna ta` persuna ohra biex jiekol, jixrob, jinhasel, jilbes, jew biex juza t-‘toilet’.
UGIEGH

1. Ibni (binti) kwazi qatt ma jbati bl-ugiegh.
2. Ibni (binti) jkollu wgiegh xi kultant, imma dan ma jwaqqfux mill-attribita tieghu (bhal: imur l-iskola; jew jilghab).
3. Ibni (binti) jkun migugh ta’ sikwit. Ghall-ugiegh huwa jkollu bzonn ta’medicini (aghti l-isem tal-medicini:)
   u xi drabi l-ugiegh jwaqqfu mill-attribita tieghu.
4. Ibni (binti) jkun migugh ta’ sikwit. Ghall-ugiegh huwa jkollu bzonn ta’medicini (aghti l-isem tal-medicini:)
   u ta’ sikwit l-ugiegh jwaqqfu mill-attribita tieghu.
5. Ibni (binti) jbati minn ugiegh qawwi, li ta’spiss ma jghaddix permezz ta’medicini li jiehu (aghti l-isem tal-medicini:)
   L-ugiegh jwaqqfu mill-attribita tieghu kotinwament.

Oqjma ohra ta’ interest

1. Fejnjghix ibnek (bintek)?
   (a) id-dar
   (b) fi stitut
2. It-tifel (tifla) tieghek x’ tip ta’ skola jmur?
   (a) skola normali
   (b) skola ghal tfal bi bzonnijiet specjali
   (c) ma jmurx skola
3. It-tifel (tifla) tieghek kemm ifalli mill-iskola minhabba l-mard?
   (a) inqas min 4 gimghat fis sena
   (b) bejn 4-12 il-gimgha fis sena
   (c) iktar min 3 xhur fis sena
4. It-tifel (tifla) tieghek qieghedjiehu xi rnedicini regolari?
   (a) iva (aghti l-isem tal-medicini:)
   (b) le
5. It-tifel (tifla) tieghek qatt dahal l-isptar?
   (a) le
   (b) iva Kemm-il darba? ___
Appendix IV

QUALITY OF LIFE FOLLOW UP OF CHILDREN BORN IN 1990.

15th September 1996.

Dear Parent,

My name is Dr. Stephanie Xuereb and I am a doctor working in the School Medical Service. I am looking into the quality of life of children (born at St.Luke’s Hospital in the year 1990) who at birth required admission to the Special Care Baby Unit (SCBU). The study is supported by both the Public Health and Paediatric departments.

I have enclosed a questionnaire which should only take a few minutes of your time to complete. Please fill in either one of the two questionnaires - the English or the Maltese translation - according to your preference. There is also a stamped, addressed envelope for you to post the questionnaire back to me as soon as possible. All information gathered from this questionnaire is strictly confidential and at no point will information on individual children be disclosed. I have included your child’s name on the questionnaire as an aid to trace back, in case of any difficulty in filling in the questionnaire.

If you have any questions please feel free to ring me on the following number: 370156.

Thank you for your time and co-operation.

Yours sincerely,

Dr. Stephanie Xuereb M.D., D.C.H. (Lond).
Appendix V

IL-KWALITA TAL-HAJJA ILLUM TAT-TFAL LI TWIELDU FL-1990.

15 ta’ Settembru 1996

Ghaziz genitur,


Jekk ikollok xi diffikulta biex timla l-kwestjonarju, tista ccempilli fuq telefon 370156.

Nirringrazzjak bil-quddiem tal-ghajnuna u l-ko-operazzjoni tieghek.

Dejjem tieghek,

Dr. Stephanie Xuereb M.D., D.C.H.(Lond).
Appendix VI

Detailed Tabulated Results by Gender, Gestational Age, and Birthweight.

Table 6. Frequencies of levels within attributes in case children weighing < 1500 g at birth. (n=19)

<table>
<thead>
<tr>
<th>Attribute level</th>
<th>Hearing</th>
<th>Vision</th>
<th>Speech</th>
<th>Mobility</th>
<th>Emotion</th>
<th>Learning</th>
<th>Self care</th>
<th>Pain</th>
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</tr>
</tbody>
</table>

* 1 invalid entry in the pain category was excluded.

Table 7. Frequencies of levels within attributes in case children weighing 1500-2499g at birth. (n=43)

<table>
<thead>
<tr>
<th>Attribute level</th>
<th>Hearing</th>
<th>Vision</th>
<th>Speech</th>
<th>Mobility</th>
<th>Emotion</th>
<th>Learning</th>
<th>Self care</th>
<th>Pain</th>
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</tr>
</tbody>
</table>

* 2 invalid entries in the pain category were excluded.

Table 8. Frequencies of levels within attributes in case children weighing >/= 2500g at birth. (n=85)

<table>
<thead>
<tr>
<th>Attribute level</th>
<th>Hearing</th>
<th>Vision</th>
<th>Speech</th>
<th>Mobility</th>
<th>Emotion</th>
<th>Learning</th>
<th>Self care</th>
<th>Pain</th>
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</tr>
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</tbody>
</table>

* 1 invalid entry in the emotion category was excluded.
Table 9. Frequencies of levels within attributes in control children weighing 1500-2499g at birth. (n=12)

<table>
<thead>
<tr>
<th>Attribute level</th>
<th>Hearing</th>
<th>Vision</th>
<th>Speech</th>
<th>Mobility</th>
<th>Emotion</th>
<th>Learning</th>
<th>Self care</th>
<th>Pain</th>
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</thead>
<tbody>
<tr>
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<td>11</td>
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<td>11</td>
<td>12</td>
<td>10</td>
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<td>1</td>
<td>0</td>
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<td>1</td>
<td>0</td>
<td>1</td>
</tr>
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<td>0</td>
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<td>0</td>
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</tbody>
</table>

Table 10. Frequencies of levels within attributes in control children weighing ≥2500g at birth. (n=161)

<table>
<thead>
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<th>Attribute level</th>
<th>Hearing</th>
<th>Vision</th>
<th>Speech</th>
<th>Mobility</th>
<th>Emotion</th>
<th>Learning</th>
<th>Self care</th>
<th>Pain</th>
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<tbody>
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</tbody>
</table>

* 1 invalid entry in the vision category and 2 invalid entries in the pain categories were excluded.

Table 11. Frequencies of levels within attributes in case children born before 37 completed weeks of pregnancy. (n=78)

<table>
<thead>
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<th>Attribute level</th>
<th>Hearing</th>
<th>Vision</th>
<th>Speech</th>
<th>Mobility</th>
<th>Emotion</th>
<th>Learning</th>
<th>Self care</th>
<th>Pain</th>
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</table>

* 1 invalid entry in the emotion category and 3 invalid entries in the pain categories were excluded.
Table 12. Frequencies of levels within attributes in case children born after 37 completed weeks of pregnancy. (n=69)

<table>
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<tr>
<th>Attribute level</th>
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<th>Speech</th>
<th>Mobility</th>
<th>Emotion</th>
<th>Learning</th>
<th>Self care</th>
<th>Pain</th>
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Table 13. Frequencies of levels within attributes in control children born before 37 completed weeks of pregnancy. (n=11)

<table>
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<tr>
<th>Attribute level</th>
<th>Hearing</th>
<th>Vision</th>
<th>Speech</th>
<th>Mobility</th>
<th>Emotion</th>
<th>Learning</th>
<th>Self care</th>
<th>Pain</th>
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Table 14. Frequencies of levels within attributes in control children born after 37 completed weeks of pregnancy. (n=162)

<table>
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<th>Vision</th>
<th>Speech</th>
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<th>Emotion</th>
<th>Learning</th>
<th>Self care</th>
<th>Pain</th>
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</tbody>
</table>

* 2 invalid entries in the pain categories were excluded.
Table 15. Frequencies of levels within attributes in female case children. \((n=67)\)

<table>
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<th>Hearing</th>
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<th>Speech</th>
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<th>Emotion</th>
<th>Learning</th>
<th>Self care</th>
<th>Pain</th>
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</tbody>
</table>

* 3 invalid entries in the pain categories were excluded.

Table 16. Frequencies of levels within attributes in male case children. \((n=80)\)

<table>
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<th>Attribute level</th>
<th>Hearing</th>
<th>Vision</th>
<th>Speech</th>
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<th>Emotion</th>
<th>Learning</th>
<th>Self care</th>
<th>Pain</th>
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</tr>
</tbody>
</table>

* 1 invalid entry in the emotion category was excluded.

Table 17. Frequencies of levels within attributes in female control children. \((n=79)\)

<table>
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<th>Attribute level</th>
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<th>Vision</th>
<th>Speech</th>
<th>Mobility</th>
<th>Emotion</th>
<th>Learning</th>
<th>Self care</th>
<th>Pain</th>
</tr>
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</tr>
</tbody>
</table>

* 1 invalid entry in the pain category was excluded.
Table 18. Frequencies of levels within attributes in male control children. (n=94)

<table>
<thead>
<tr>
<th>Attribute level</th>
<th>Hearing</th>
<th>Vision</th>
<th>Speech</th>
<th>Mobility</th>
<th>Emotion</th>
<th>Learning</th>
<th>Self care</th>
<th>Pain</th>
</tr>
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<td>1</td>
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</tr>
</tbody>
</table>

* 1 invalid entry in the pain category was excluded.