

Quality of life in young adults with very low birth weight

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Abstract

Objectives—To assess quality of life (QoL) in a group of young adults born in 1980–1982 with very low birth weight (VLBW) and to compare this with a reference group and a similar cohort born eight years earlier.

Design—Telephone interview using a fully structured questionnaire.

Setting—Level 3 neonatal intensive care unit.

Patients—VLBW group (n = 92, 90% participation rate), LBW group (n = 119, 86%), normal birth weight/reference group (n = 69, 75%).

Main outcome measures—Objective and subjective QoL.

Results—Objective QoL in the VLBW subgroup who did not report a handicap or chronic health problem was lower than in the reference group (median 0.79 v 0.84, p = 0.02). Objective QoL was 0.81 in the similar LBW subgroup whereas it was only 0.72 in the group of 13 VLBW and nine LBW subjects who reported a handicap or chronic health problem. Interestingly, subjective QoL did not differ between the VLBW subgroup and the reference group (median 0.87 v 0.88, p = 0.5). On comparing the VLBW subgroup in the 1980–1982 cohort with the similar VLBW subgroup in the 1971–1974 cohort, objective QoL had apparently increased.

Conclusion—The VLBW young adults had a lower objective QoL than the reference group, whereas the subjective QoL was similar. Objective QoL in Danish youngsters has apparently increased over the past eight years.

(Arch Dis Child Fetal Neonatal Ed 2001;85:F165–F169)

Keywords: very low birth weight; quality of life; follow up; telephone interview

In the 1970s, neonatologists in Denmark restricted treatment of infants of very low birth weight (VLBW), but at the beginning of the

1980s more intensive treatment helped decrease mortality. This meant that smaller infants survived. With the increased survival, did the risk of long term sequelae increase?

We have previously evaluated quality of life (QoL) in young adults (18–20 years) born with very low birth weight (< 1500 g, VLBW); this was in 1971–1974 (the 1971–1974 cohort).¹ Survival to discharge from neonatal care was 48%. No statistically significant difference in QoL was found between a reference group with normal birth weight (NBW) and a VLBW subgroup who did not have any physical handicap or chronic health problems.

The aim of this study was to examine whether this had changed for the worse. A VLBW cohort born between 1980 and 1982 (81% survival to discharge) was compared with a reference group. As the same tool for measuring QoL was used, the results of the two studies were compared.

Subjects and methods

Our study included three groups:

(1) VLBW group: < 1500 g. A consecutive series of subjects who were born or transferred to Rigshospitalet during the first 4 days of life, between 1980 and 1982.

(2) LBW group: > 1500 g and < 2300 g. A consecutive series of infants born at Rigshospitalet, omitting every fourth, between 1980 and 1982.

(3) Reference (NBW) group: normal birth weight (> 2500 g). The subjects in this group were born after 37–40 gestational weeks with an Apgar score of 9 or 10 at one minute and normal birth weight. They were selected in such a way that every 40th inborn at Rigshospitalet in the same period was included.

The VLBW group was followed up at 2 years of age,² and all three groups were followed up at 4 years of age.³ Subjects from the VLBW and LBW groups who reported handicap or chronic health problems were grouped and analysed separately (group 4). This was carried out in agreement with the 1971–1974 study. Table 1 gives the criteria for placement in group 4. This means that, for the analysis in this paper, groups 1 and 2 consisted only of subjects who did not report such problems. Figure 1 details how the four groups were made up.

The subjects of the cohort were contacted by letter, and then interviewed by telephone. There were 65 questions, each with three to five predefined answers (the questionnaire translated into English can be found at <http://www.archdischild.com>). All interviews were performed by SJD. The interviewer was blinded to the birthweight group, but on some occasions subjects identified their group after the interview. The interviews were conducted from December 1999 to April 2000.

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Accepted 25 June 2001

Table 1 Self reported handicaps and chronic health problems in subjects of very low birth weight (VLBW), low birth weight (LBW) and normal birth weight (NBW)

Handicap/disease	VLBW (n=92)	LBW (n=119)	NBW (n=69)
Cerebral palsy	4	1	—
Impaired sight/hearing	7	5	1
Silver-Russell's syndrome	1	—	—
Physical handicap	—	1	—
Diabetes	—	1	—
Crohn's disease	—	1	—
Obsessive compulsive disorder	1	—	—
Deficit in attention and motor perception	—	—	1
Total number of subjects	13	9	2

ESTIMATION OF QOL

The questionnaire was developed from the theories of Aggernæs,⁴ who presumed that there are four fundamental classes of human need, the fulfilment of which determines QoL: (1) elementary biological need (EBN); (2) need for warm human relations (WHR); (3) need for meaningful occupations (MO); (4) need for diverse and exciting experiences (DEE).

Furthermore, he proposed that QoL has a subjective and an objective aspect. Objective QoL is based on societal standards whereas subjective QoL is based on individual life experiences and preferences. We evaluated both objective and subjective QoL.

SCORES

Scores were given according to the manual designed for the 1971–1974 study. However, we were not able to reproduce exactly the scoring for the question about occupation; being in any type of education was here classified as an occupation. This resulted in a higher score for MO. Therefore, for the comparison with the

1971–1974 cohort, a corrected QoL score that excluded the MO subscore was calculated.

Each subscore was calculated as the fraction of the highest possible score; in this way the maximum subscore is 1 and the minimum is 0. The objective QoL was calculated as the sum of the four subscores and weighted as follows: $QoL = (0.3 \times EBN) + (0.3 \times WHR) + (0.2 \times MO) + (0.2 \times DEE)$.

Subjective QoL was calculated as a modification of objective QoL. For example, if a person was asked “how often do you share time with your friends” and the answer was “never”, he/she was given 0 points for the objective QoL. However, if to the next question, “how important is the contact to you”, the subject answered “not important at all”, then the subject was given 1 point for subjective QoL, because this person fulfilled his/her own needs.

STATISTICAL ANALYSIS

As the distributions were not strictly normal, the Mann-Whitney test was used to test statistical significance of difference. We tested differences in objective and subjective QoL

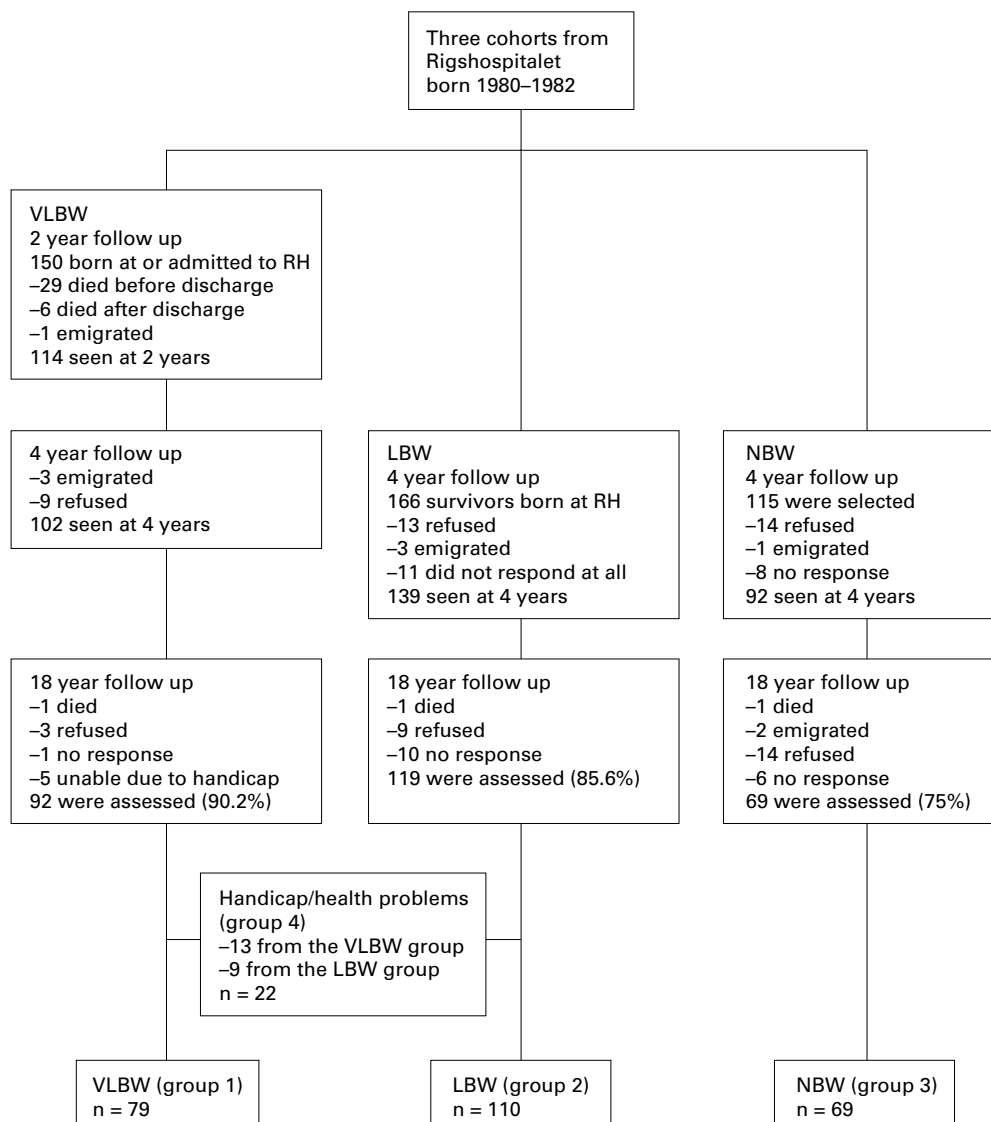


Figure 1 Make up of the four groups for analysis of quality of life.

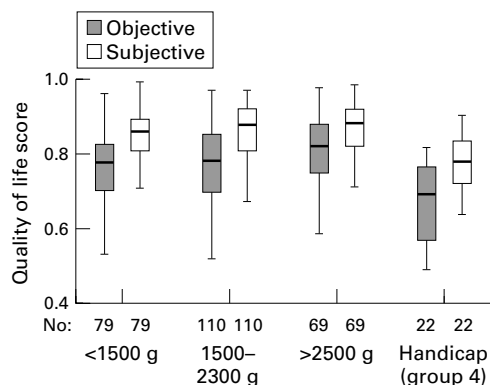


Figure 2 Objective and subjective quality of life in the four groups: the normal very low birth weight group (< 1500 g), the normal low birth weight group (1500–2300 g), the reference group (> 2500 g), and the group with handicap or chronic health problems. The box and whisker plots indicate median, 25–75th centiles, and 5–95th centiles.

between group 1 and 3, because this was done in the 1971–1974 cohort. The statistical package SPSS version 10.0 was used.

The research ethics committee of Copenhagen and Frederiksberg approved the project.

Results

COHORT 1980–1982

Ninety two VLBW subjects participated. Thirteen of these reported handicap or chronic health problems, leaving 79 “normal” VLBW subjects or 65% of the group discharged from neonatal care (table 1 and fig 1). Nine of the 119 subjects in the LBW group reported handicap or chronic health problems, leaving 110 in the “normal” LBW subgroup. The handicap/health problem group therefore comprised 22 subjects.

There was a significant difference in objective QoL between the “normal” VLBW subgroup (median 0.79, interquartile range 0.73–0.85) and the reference group (median 0.84, interquartile range 0.78–0.88) (p = 0.02) (fig 2).

Median objective QoL score in the “normal” LBW subgroup was 0.81 (interquartile range 0.72–0.88). This was not significantly different from the VLBW group, nor different from the reference group.

With regard to the subscores, significant differences between the “normal” VLBW subgroup and the reference group were present in

WHR (median 0.83 and 0.89 respectively; p < 0.01) and DEE (median 0.75 and 0.75 respectively; p < 0.05).

In contrast, there was no difference in subjective QoL among the three normal groups.

As expected, objective QoL in group 4 was significantly lower (median 0.72, interquartile range 0.63–0.82) than the reference group (p < 0.01). Even subjective QoL was significantly lower in group 4 (median 0.80, interquartile range 0.75–0.85) than the reference group (p < 0.01) (table 2).

COMPARISON WITH THE 1971–1974 COHORT

Mean corrected objective QoL score in the normal VLBW subgroup of the 1980–1982 cohort was 0.75 (25th centile 0.70) compared with 0.72 in the 1971–1974 cohort. Mean corrected objective QoL score in the reference group in the 1980–1982 cohort, however, was also higher compared with the 1971–1974 cohort (mean 0.80 v 0.76). In the 1980–1982 cohort, the 25th centile was 0.75 (fig 3). As we only had the mean scores from the 1971–1974 cohort, it was not possible to compare the two cohorts statistically in a formal way. A gross comparison can be made with reference to the interquartile ranges. Given the size of the groups, the increases from 1971–1974 to 1980–1982 are likely to be borderline significant.

Corrected subjective QoL score was marginally higher in 1980–1982 than 1971–1974 for both groups: VLBW group mean 0.85 v 0.84 and reference group mean 0.87 v 0.86, hardly statistically significant.

Discussion

RESULTS

We found a significant difference in objective QoL between the VLBW and reference groups. Several studies have shown an increased risk of educational difficulties as well as behavioural and emotional problems in VLBW infants.^{5 6} Furthermore, Ericson and Källén⁷ found an excess of low intelligence quotient (IQ) scores in VLBW boys at the age of 19. This can all be expected to influence QoL. The difference in QoL in our study, however, was only moderate, the mean value in the VLBW group corresponding to the 25th centile of the reference group (fig 2).

Table 2 Total quality of life (QoL) scores and subscores for the very low birthweight (VLBW), the low birthweight (LBW) and the normal birthweight (NBW) groups

	VLBW (n=79)		LBW (n=110)		NBW (n=69)		Handicap/group 4 (n=22)	
	Mean	Interquartile range	mean	Interquartile range	Mean	Interquartile range	Mean	Interquartile range
Objective QoL	0.78	0.73–0.85	0.79	0.72–0.88	0.81	0.78–0.88	0.72	0.63–0.82
EBN	0.76	0.68–0.86	0.76	0.65–0.86	0.77	0.67–0.87	0.59	0.49–0.67
WHR	0.80	0.72–0.89	0.82	0.77–0.89	0.84	0.78–0.94	0.73	0.61–0.83
MO	0.91	0.83–1.00	0.89	0.83–1.00	0.87	0.83–1.00	0.90	0.83–1.00
DEE	0.68	0.50–1.00	0.71	0.50–1.00	0.79	0.75–1.00	0.73	0.50–0.81
Subjective QoL	0.86	0.82–0.90	0.87	0.82–0.93	0.87	0.83–0.91	0.80	0.75–0.85
EBN	0.81	0.73–0.90	0.82	0.71–0.92	0.81	0.74–0.91	0.67	0.58–0.73
WHR	0.82	0.78–0.89	0.85	0.78–0.94	0.86	0.83–0.94	0.77	0.67–0.83
MO	0.91	0.83–1.00	0.89	0.83–1.00	0.87	0.83–1.00	0.90	0.83–1.00
DEE	0.93	1.00–1.00	0.95	1.00–1.00	0.95	1.00–1.00	0.93	0.94–1.00

Means are given to allow comparison with the 1971–74 cohort.

EBN, Elementary biological needs; WHR, warm human relations; MO, meaningful occupation; DEE, diverse and exciting experiences.

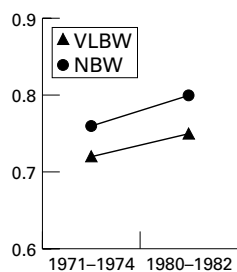


Figure 3 Mean corrected objective QoL score in the 1971-1974 and the 1980-1982 cohorts of very low birthweight (VLBW) subjects who did not report a handicap or chronic health problem and the normal birthweight (NBW) reference groups. The difference between the VLBW and NBW groups was significant in 1980-1984 ($p = 0.02$), whereas in 1971-1974 it was not. (The corrected score excluded the subscore on meaningful occupation, which was scored differently in the two cohorts.)

The results refer to the subgroup of VLBW subjects who did not report a handicap or chronic health problem. In our cohort, the “normal” VLBW subgroup also scored lower on cognitive and motor tests when assessed at 4 years of age. Compared with the reference group, the mean of the “normal” VLBW subgroup was at -1 SD—that is, at the 16th centile. This means that, in statistical terms, the deficit in objective QoL at 18 years of age tended to be less than the deficit at neurodevelopmental testing at 4 years of age.

Subjective QoL did not differ among the three groups. This may be explained by the ability of humans to adapt to and accept situations in which they are placed. For example, disabled people may use denial as a defence mechanism. Professionals tend to have a different perspective when judging QoL.^{8,9} On the other hand, the ability to accept fate is a valuable asset of human nature. In a free society, the final judgment of QoL must rest with the individual.

When comparing the two cohorts eight years apart, we found a significant increase in objective QoL in the reference groups from 1972-1974 to 1980-1982. As both groups were selected randomly from the birth registry of Rigshospitalet, QoL was expected to be constant. Can it be assumed that QoL is constant over time, if measured appropriately, like an IQ score? Is it possible to assess QoL at all over time? We used the same questionnaire for the 1980-1982 cohort as was used for the 1971-1974 cohort (excluding MO). Although it cannot be excluded that our questions were interpreted differently, they were simple and the answers fully structured. The 1980-1982 cohort had a higher score, not a lower one as would be expected if other pastimes had taken over, such as watching videos, playing computer games, etc. We favour the interpretation that the increase in objective QoL is a result of social change over the last decade. The increasing affluence of young people could be why the subscore DEE increased from the 1971-1974 to the 1980-1982 cohort. This subscore contained questions about spare time—for example, sport, travelling, going to the cinema or theatre.

In the “normal” VLBW subgroup, objective QoL also increased, although not quite as much as in the reference groups. As a result, the difference between the VLBW and the reference group was significant for the 1980-1982 cohort, whereas it was not in the 1971-1974 cohort.

The conclusion may be that the “normal” VLBW subgroup benefitted, although not fully, from the enriched life achieved during recent years by young adults in Denmark. It should be noted though that the change in difference between the VLBW and reference groups is small and probably statistically insignificant. The change over time seen for the “normal” VLBW subgroup—regardless of how it is interpreted—would not appear to be a large price to pay for the increase in survival from 48% to 81%.

POPULATION

In the 1971-1974 study, the group of VLBW young adults with handicap or chronic health problems was analysed separately, but subjects in the reference group with handicap and chronic health problems were not. This could be considered a possible bias, but the argument for this procedure was to compare a group of “normal” VLBW children with an average group with normal birth weight. However, those with mental retardation who are able to complete the interview do not necessarily classify themselves as handicapped.

The two VLBW cohorts were not identical. Although both were composed of consecutive admissions from the same region, the survival rate was higher in 1980-1982 than 1971-1974 and the birthweight distribution of the participants in the QoL studies was shifted towards lower birth weights in the later period ($p < 0.05$). For example, 13 subjects weighed less than 1000 g in the 1980-1982 cohort compared with only two in 1971-1974. Unfortunately, gestational age and social group of the parents were not available for the 1971-1974 cohort. It is likely that the distribution of gestational age also shifted to the left with time and unlikely that the social group changed much. However, a formal detailed comparison is not possible.

The participation rate in the VLBW group was 90.2%. Five subjects could not be interviewed because of severe handicap. There were only four subjects (3.9%) for whom we had no data at all.

In the LBW group, 85.6 participated. The participation rate in the reference group was 75%; motivation of these subjects may have been lower.

Of those who did not respond after two letters, 33 with a recorded telephone number were phoned. Three did not want to participate, but 30 agreed to participate, and their QoL scores did not differ. Thus it may be expected that the scores of those who could not be contacted did not differ either. We decided from the outset to exclude children who did not participate in the four year follow up. This may have made our sample slightly underrepresentative.

THE METHOD

Telephone interviewing has been criticised as a method, but compared with face to face interviewing, the quality of data from telephone interviews is high.¹⁰ Nevertheless, some aspects should be discussed. Firstly, answers may be less than adequate. However, the questionnaire was structured with two to five simple answer choices, so this is unlikely to detract from our study. Elderly subjects or subjects of foreign origin may not express themselves fully and clearly on the telephone for psychological, cultural, or language reasons. In our study, all subjects were born in Denmark and were young. The five subjects who were, according to family or carers, unable to complete the interview by phone, would probably have been unable to complete a face to face interview also.

Furthermore, the anonymity and social distance provided by the telephone may make it easier to answer personal questions.¹⁰ The questionnaire touched on sensitive issues, such as love and abuse of alcohol and drugs. Some studies have shown that there is greater participation in telephone interviewing than personal interviewing. We decided that this was particularly relevant for our age group.

QOL THEORY

Studies that try to assess global QoL may help to evaluate the outcome of neonatal care and therefore help in the counselling of parents. However, QoL is a controversial concept. We chose to use the Aggernæs theory because it has previously been used successfully, we believe in the idea that life has some universal dimensions, and it is unique in assessing both objective and subjective QoL.¹ The last of these is important for several reasons: (a) people often neglect needs they consider unattainable; (b) needs that are satisfied with no effort are not considered to be needs; (c) actual needs may differ from person to person. Therefore life is objectively valuable as well as subjectively valuable.

CONCLUSION

We can conclude from the results that the normal VLBW subgroup has a lower objective QoL score than the reference group, whereas

subjective QoL scores were not different. Group 4 had lower QoL scores, objective as well as subjective. Looking at the change over time, from the earlier study of the 1971–1974 cohort to the present 1980–1982 cohort, the QoL scores of the normal VLBW subgroup increased, although not quite as much as the scores of the reference group.

- 1 Bjerager M, Steensberg J, Greisen G. Quality of life among young adults born with very low birth-weights. *Acta Paediatr* 1995;**84**:1339–43.
- 2 Greisen G, Petersen MB, Pedersen SA, *et al.* Status at two years of 121 very low birth weight survivors related to neonatal intraventricular haemorrhage and mode of delivery. *Acta Paediatr Scand* 1986;**75**:24–30.
- 3 Bloch Petersen M, Greisen G, Kovacs R, *et al.* Status at four years of age in children weighing 2,300 g or less at birth. *Dan Med Bull* 1990;**37**:546–52.
- 4 Aggernæs A. *Livskvalitet*. Copenhagen: FADLs Forlag, 1988.
- 5 Stjernqvist K, Svenningsen NW. Ten-year follow-up of children born before 29 gestational weeks: health, cognitive development, behaviour and school achievement. *Acta Paediatr* 1999;**88**:557–62.
- 6 Stevenson CJ, Blacburn P, Pharoah POD. Longitudinal study of behaviour disorders in low birthweight infants. *Arch Dis Child Fetal Neonatal Ed* 1999;**81**:F5–9.
- 7 Ericson A, Källén B. Very low birthweight boys at the age of 19. *Arch Dis Child Fetal Neonatal Ed* 1998;**78**:F171–4.
- 8 Saigal S, Hoult LA, Streiner DL, *et al.* School difficulties at adolescence in a regional cohort of children who were extremely low birth weight. *Pediatrics* 2000;**105**:325–31.
- 9 Saigal S, Feeny D, Rosenbaum P, *et al.* Self-perceived health status and health-related quality of life of extremely low-birth-weight infants at adolescence. *JAMA* 1996;**276**:453–9.
- 10 Eszter K, Egsomse L, Noordhoek J. *Datakvalitet ved telefoninterview*. Copenhagen: Socialforskningsinstituttet, 1986.