Quality of life in young adults with very low birth weight

S J Dinesen, G Greisen

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 vs 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 vs 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.

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). 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, and all three groups were followed up at 4 years of age. 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.
ESTIMATION OF QoL
The questionnaire was developed from the theories of Aggermanns, who presumed that there are four fundamental classes of human need, the fulfillment 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.
Very low birth weight and quality of life

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

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.

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

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

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.

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

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
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. 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%.
Furthermore, the anonymity and social distance provided by the telephone may make it easier to answer personal questions. 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. 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.