Health related quality of life of former very preterm infants in adulthood

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Abstract

Aim: To assess health related quality of life of young adults born very preterm compared with a term control group. Methods: A cohort of preterm infants <1250 g and a term control group, both born between 1983-1985, were surveyed as adults at the median age of 23 years. Questionnaires including the SF 36 and a modified lifestyle questionnaire assessed quality of life, health attitudes, height and weight, chronic diseases, medication and drug consumption. Results: 52 preterms and 75 controls matched for age and sex participated in the study. There were no significant differences in the quality of life as assessed by SF 36. Former preterms were significantly smaller than their term controls but not so for body mass index. The overall consumption of illicit drugs was significantly lower in former preterms. Moreover, former preterms went significantly less often in for sports. There was a trend for higher prevalence of chronic diseases in male compared to female preterms, but their use of medication was significantly lower. Conclusion: Adults, born very preterm show no significant differences in their quality of life when compared to controls in early adulthood. However, based on their lifestyle and health disadvantages, male preterm subjects constitute a risk group when entering early adulthood with a clear need for continued attention.
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HRQOL, outcome, questionnaire, SF 36, VLBW

Abbreviations

SF 36 Short Form 36 Health Survey
HRQOL Health Related Quality of Life
PCS Physical Component Summary (Physical health summary score)
MCS Mental Component Summary (Mental health summary score)

Competing interests

The authors declare that they have no competing interests.

Abstract

Aim: To assess health related quality of life of young adults born very preterm compared with a term control group. Methods: A cohort of preterm infants <1250 g and a term control group, both born between 1983-1985, were surveyed as adults at the median age of 23 years. Questionnaires including the SF 36 and a modified lifestyle questionnaire assessed quality of life, health attitudes, height and weight, chronic diseases, medication and drug consumption. Results: 52 preterms and 75 controls matched for age and sex participated in the study. There were no significant differences in the quality of life as assessed by SF 36. Former preterms were significantly smaller than their term controls but not so for body mass index. The overall consumption of illicit drugs was significantly lower in former preterms. Moreover, former preterms went significantly less often in for sports. There was a trend for higher prevalence of chronic diseases in male compared to female preterms, but their use of
medication was significantly lower. **Conclusion:** Adults, born very preterm show no significant differences in their quality of life when compared to controls in early adulthood. However, based on their lifestyle and health disadvantages, male preterm subjects constitute a risk group when entering early adulthood with a clear need for continued attention.

**Key Notes:** Preterm individuals show higher rates of chronic diseases, difficulties in growth attainment, behavioural problems and poorer academic performance during childhood and adolescence. Our study shows that adults born preterm show no significant differences in their quality of life when compared to controls in adulthood. However, male preterm subjects - based on their lifestyle and health disadvantages- constitute a risk group when entering adulthood with a need for continued attention.

**Background**

Tremendous advances in perinatal and neonatal medicine over the last four decades, and especially since the early 90’s such as antenatal lung maturation, surfactant replacement therapy, continuous positive airway pressure (CPAP) or new techniques of mechanical ventilation have lead to a continuous increase in survival of preterm neonates, especially of infants with extremely low gestational age (ELGA) or birth weight (ELBW). Unfortunately, this success in survival has not been paralleled by a significant decrease in morbidity in these very premature infants. On the contrary, several follow-up studies found an increase in long-term disability [1, 2]. Therapeutical success therefore, should not be measured any longer only in terms of survival rate but also as objective disability scores, and by the subjective assessment of the quality of life as perceived by the concerned person. This includes physical, psychological and social well-being as defined by the WHO as well as
the domains of living independently from the family, of friendships and achievement of educational, occupational and personal aims [3].

Previous studies comparing former preterm individuals with control persons born at term have shown higher rates of chronic diseases, difficulties in growth attainment, poorer cognitive function, behavioural problems, poorer academic performance during childhood and adolescence [4-7]. Results however, differ when looking at the early adulthood [8-11]. Our study therefore, aimed at answering the question ‘how do former preterms born in the 80’s manage their life nowadays when reaching early adulthood’? This study evaluates health attitudes and self-perceived health status (quality of life) of former preterms now in their 3rd decade of life as compared with a control group born at term and matched for age and sex. Our hypothesis was that there would be no significant difference between both groups regarding health related quality of life (HRQOL).

Patients and Methods

The study group included preterm infants (PT group) with a birth weight below 1250 g who were either born at the University Hospital Zurich (inborns) or transferred to the NICU after birth (outborns). The recruitment period was between January 1st 1983 and December 31st 1985. Control subjects born at term (T group) were matched for gender and age (born +/- 14 days around the expected term of the study subject), with an initial intention to recruit three controls per each subject. They had to fulfil the following entry criteria: single pregnancy, born at term, no postnatal admission to the neonatal ward, no problems related to pregnancy or birth in the mother or newborn.

Demographics

Socioeconomic data (education and occupation) of the parents were obtained by a separate questionnaire. The socioeconomic status (SES) [12] was estimated using a 12 points scale based on maternal education and paternal occupation, with 2 being the lowest and 12 the highest level. Maternal obstetric history, perinatal and neonatal data of the subjects and control infants were extracted from hospital charts.
**Questionnaires**

The SF 36 exploring HRQOL and a questionnaire, assessing health attitudes were sent to all participants. The SF 36 is a short questionnaire comprising 36 items; it is standardized and well validated for measuring mental and physical health in the 4 weeks preceding the assessment. The physical health summary score (PCS) contains the following 4 subscales: physical functioning (10 items), role limitation due to physical problems (4 items), bodily pain (2 items) and general health perception (5 items). The mental health summary score (MCS) assesses the following 4 subscales: role limitations due to emotional problems (3 items), vitality (4 items), social functioning (2 items) and mental health. Health attitudes like drug, alcohol and tobacco consumption (first experience and regular consumption), sport activities and body height, weight and body mass index (BMI) were assessed by questions extracted from the questionnaire designed by Dinesen and Greisen [11]. All questionnaires were written in German language.

**Statistics**

The SPSS software package version 16.0 was used for statistical analysis. Differences between subjects and controls were analyzed with the Student’s t-test and the Chi square test where appropriate. In case of non normal distribution, the Mann Whitney U Test was used.

**Ethical approval**

The institutional ethics boards of the University Children’s Hospital Zurich and of the Canton of Zurich approved the study protocol.
Results

134 preterm infants were born at the University Hospital Zurich during the defined study period with a BW below 1250 g. 58/134 died (43%), and 67 out of the 76 survivors took part in regular follow up assessments at the Unit of Growth and Development at the Children’s Hospital Zurich. Moreover, 13 outborn preterm infants fulfilling the same inclusion criteria were included. Therefore, a total 80 former preterm individuals matched the enrolment criteria into the preterm group (PT). 17 (21%) refused to take part or sending back questionnaires, which were not complete and another 11 (14 %) had moved and could not be traced back. Therefore 52 out of these (65%) agreed to take part in our study, and they constituted the PT study group. Because of his handicaps, one participant was supported by his mother when answering the questionnaire, and two further participants answered via interview. There were no significant differences regarding gestational age (GA), birth weight (BW), gender and neonatal complications (mechanical ventilation, NEC, IVH, ROP and cerebral palsy) between participants and non-participants.

165 adults (mean age of 23.0 years) born at term were contacted by letter and invited to take part in this study as a control group. 53 (32 %) did not reply after two attempts to contact them, 14 (9%) refused participation, 2 had died, and 9 control persons could not be found. 87 (53%) initially agreed to participate, and eventually 78/87 (90%) returned the questionnaires. Subsequently, 3 control subjects were excluded because their matched study subjects did not send in the questionnaires. Therefore, the control group (T group) consisted of 75 subjects born at term.

The demographic data of study participants are summarized in Table 1.

SF 36 Questionnaire

There were no significant differences in any subscale or in the PCS and MCS between the study group and the control group. With regard to gender, preterm males scored lower than their male peers in all domains, but only in the subscale ‘Physical Functioning’ did this difference reach statistical significance (mean PT 90.0 vs. T 97.8; p= 0.02). The comparison within preterm subjects showed
lower scorings for male preterms in all domains, except for the subscale ‘Bodily Pain’. Female
preterms scored equally in all domains, and even significantly higher in the subscale ‘Role Limitation
due to Emotional Problems’ (mean PT 90.0 vs. T 83.0; p= 0.04) when compared with their female
controls. These results are shown in Figure 1 A/B.

**Health attitudes**

Compared with their control peers, former preterms tended to smoke more often (OR 1.19;
95% CI, 0.58-2.44). Alcohol consumption was approximately identical in preterm and term subjects.
Cannabis consumption, however, was significantly less frequent among preterms when looking at who
ever consumed cannabis (OR 0.25, 95% CI; 0.10-0.59; p<0.01) (Figure 2). The age at their first
cannabis experience was the same for both groups (PT= 16.5 years vs. T=15.7 years; n.s). Importantly,
there was a low experience regarding the use of cocaine, LSD and ecstasy for both groups, again
without significant difference (OR 0.34, 95% CI; 0.07-1.65; n.s).

With regard to sports, there was a significant difference with more term controls practicing
sports than preterms, either in general (OR 0.43; 95% CI; 0.18-0.99; p= 0.04), or on a daily basis.
Compared by gender, significantly less male preterms than male peers took exercise (OR 0.2; 95% CI
0.05-0.88; p=0.03). Interestingly, no such difference could be shown between female subjects and
controls (OR 0.62; 95% CI; 0.21-1.81; n.s).

**Chronic Diseases**

Chronic diseases tended to be more common in former preterm subjects than among their
term peers (chronic diseases PT/T: OR 1.23; 95% CI; 0.54-2.79; n.s). The use of prescription drugs
was similar in both groups (medication PT/T: OR 0.98; 95%CI; 0.38-2.50; n.s). When looking at
gender differences, male preterms not only suffered significantly more often from chronic diseases
than their male controls (chronic diseases male PT/T: OR 7.00; 95% CI; 1.27-38.47; p=0.02), but also
tended to suffer more often when compared to female preterms (chronic diseases male/female PT: OR
2.56; 95% CI; 0.73-8.97; n.s). Regular medication intake tended to be more frequent in female
Discussion

Our findings show that preterm individuals describe themselves as similar to their peers, both in terms of physical and psychological functions. The almost similar scoring between preterm and term controls in the SF 36 confirms findings of previous studies [13-15]. Interestingly, we were able to show that female preterm subjects scored higher when compared to male preterms and to female controls. Importantly, our results did not confirm the lower scoring in mental health in preterm individuals but showed a lower physical functioning score in male preterms which is in accordance with the studies mentioned above.

Chronic diseases are common in preterm subjects as described in a recent study by Saigal and co-workers [13]. In our study the difference between preterm and their term born peers was lower than expected. This can be explained by a different way former preterm subjects cope with their limitations, and possibly by methodical differences of the questionnaires used. Nevertheless, our results show a health disadvantage for male preterm subjects in their early adulthood. Interestingly, this is in contrast with a less frequent report of prescription drugs in male preterms when comparing with female preterms in this questionnaire survey. A possible interpretation of his observation might be a different health attitude and coping strategy with medical conditions between male and female individuals, such as frequently reported for male and female adults within the general population when it comes to compare differences in health status and in seeking medical advice and help [16, 17].

Our results did not reveal any significant differences in alcohol and tobacco use between preterm and term subjects, but we found a trend towards an increasingly regular tobacco and alcohol use in preterms, and especially in former preterm male study participants. This finding is in contrast with recent studies, which describe significantly lower alcohol and tobacco consumption in preterm individuals as a result of their lower risk taking behaviour [14, 18]. Against the background of a higher
risk of cardiovascular diseases in former preterm individuals, these results are of major concern [19-21]. Our observations regarding illegal drug use in preterm subjects corroborate results of former studies [14, 18, 22]. The lower attendance in sport activities, especially of male preterms, might result from their lower physical functioning, as seen in the SF 36.

Our study was based on a geographically defined cohort born at the beginning of the 80’s at the University Hospital Zurich, a tertiary perinatal centre in Switzerland. There are some limitations that deserve discussion. First, there were only few participants with major disabilities in the PT group. This could be explained by the high mortality in neonates with severe complications at that time. All former preterm infants had developmental follow-up examinations, the first at the age of 2 years with 1 individual diagnosed with cerebral palsy in the participants and 1 in the non-participants. Secondly, recruiting and motivating former preterm as well as term subjects in their early adulthood age to voluntarily take time and efforts in answering questionnaires proved to be more difficult than expected. Thirdly and importantly, the SF 36 might not be the most appropriate and discriminative questionnaire to evaluate the HRQOL of a cohort of former preterms without severe disabilities in their mid-twenties. Aspects such as education, profession, friendship and partnership seem more relevant and would allow stronger conclusions to be drawn about the most important factors influencing the HRQOL at that age, e.g. the ability to live an independent and self-determined life.

**Conclusion**

These results based on self-perception confirm our hypothesis that in absence of severe disabilities former preterm individuals tend to satisfyingly overcome the problems related to their prematurity when entering into early adulthood. Nevertheless and based on their health attitudes and health disadvantages, male preterms must be considered as especially vulnerable. To prevent an increase in their risk of developing a metabolic syndrome, at which they are at higher risk due to their lifestyle, there is a need for more information and education, both of the parents and of the individuals but also of their health care professionals. Additional follow-up studies in later adulthood are essential.
to assess potential changes in health status, health attitudes and in occupational status, but also in partnership and parenthood. In our view, a questionnaire including more relevant aspects influencing quality of life should be developed and validated for further investigations of the HRQOL of young adults without severe disabilities.

Acknowledgements

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References


# Tables and Figures

## Table 1

Demographic Data

<table>
<thead>
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<th></th>
<th>Preterms (n = 52)</th>
<th>Term Control (n = 75)</th>
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<tr>
<td><strong>Gender</strong></td>
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<tr>
<td>(male : female)</td>
<td>21 : 31</td>
<td>23 : 52</td>
</tr>
<tr>
<td></td>
<td>(40: 60%)</td>
<td>(31: 69%)</td>
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<tr>
<td><strong>Gestational Age (wks)</strong></td>
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<tr>
<td>(Mean; range)</td>
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<tr>
<td></td>
<td>(25.7 - 35.1)</td>
<td>(38.0 - 42.0)</td>
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<td><strong>Birthweight (g)</strong></td>
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<td></td>
</tr>
<tr>
<td>(Mean; range)</td>
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<td>3400</td>
</tr>
<tr>
<td></td>
<td>(680 - 1250)</td>
<td>(2360 - 4440)</td>
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<tr>
<td><strong>Cerebral Palsy (at 2 years)</strong></td>
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<tr>
<td><strong>Mean age at assessment (years)</strong></td>
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<td>23.0</td>
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<tr>
<td>Height at assessment (cm; Mean)</td>
<td>176.3* (male)</td>
<td>180.8* (male)</td>
</tr>
<tr>
<td>--------------------------------</td>
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</table>

| BMI at assessment | | | |
|-------------------|---------------|---------------|---------------|---------------|
| Underweight (<18.5) | 2 (4%) | 4 (6%) | |
| Normal (18.5-25) | 37 (71%) | 61 (81%) | |
| Overweight (25-30) | 9 (17%) | 8 (10%) | |
| Obesity (>30) | 4 (8%) | 2 (3%) | |

<table>
<thead>
<tr>
<th>Parental SES (Mean; range)</th>
<th>7.2* (2.0 - 12.0)</th>
<th>9.0* (5.0 - 12.0)</th>
</tr>
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</table>

*p<0.05
Fig. 1 A: Results of the male participants in the SF 36

PF: Physical functioning *; RP: Role-Physical; BP: Bodily Pain; GHP: General Health Perception; V: Vitality; SF: Social Functioning; RE: Role-Emotional; MH: Mental Health

*p < 0.05
Fig. 1 B: Results of the female participants in the SF 36

PF: Physical functioning; RP: Role-Physical; BP: Bodily Pain; GHP: General Health Perception; V: Vitality; SF: Social Functioning; RE: Role-Emotional *; MH: Mental Health

*p<0.05

Figure 2

Odds Ratio for health attitudes of Preterms/Term Controls