

Title: Very low birthweight young adults: parental assessments of their health and social functioning

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Introduction:

The survival of very low birthweight (VLBW) infants (birthweight <1500g) has improved significantly since the 1980's due to medical advancements, with current survival rates exceeding 90%. However, as increasing numbers of VLBW individuals are reaching adulthood, concerns have arisen that these individuals experience higher rates of health, disability and developmental problems than other young adults. Subsequently, there has been considerable interest in the long term outcomes of this group. The New Zealand VLBW study is a national study which has investigated a group of VLBW babies born in 1986 over time. The health, developmental and functional outcomes of these individuals have been assessed at several stages of the life course and compared against a group of other non-VLBW infants born in the same year (a control group). The next stage of this study is investigating the health and wellbeing of these individuals at 27/28 years and is currently in progress. This research project originates from the above study and is interested in how the parents of these young adults regard their long term outcomes.

Aim:

The primary objective of this study is to assess how parents of VLBW infants born in 1986 in New Zealand view the health, wellbeing and social functioning of their young adults at 27/28 years, compared to control parents. A second objective is to identify whether differences exist between parental and self-assessments of young adult health, wellbeing and function. Only a subset of the full group of VLBW and control parents could be contacted within the time frame of this studentship and the resulting sample size may be too small to detect significant findings. This research will however enable refinement of the study procedures/questions that will later be administered to the complete set of study parents, as well as generating some preliminary results and trends which can guide and inform ongoing research in the area.

Method:

40 parents of VLBW young adults (VLBW parents) and 30 parents of non-VLBW young adults (control parents) were asked a questionnaire over the telephone regarding their offspring's health and quality of life, social functioning, employment/education, fitness/coordination, personality and behaviour. The questionnaire was mostly structured (e.g. answers on a scale from "very good" to "very poor") but also included a few open format components which allowed parents to freely express their own ideas and thoughts. The answers, along with some self-assessment data from the NZ VLBW study, were entered into an electronic database. Structured components were then analysed under biostatistician direction using the statistical package SPSS. Open format components were transcribed and categorised based on topics discussed and the resulting emergent themes identified (thematic analysis).

Results:

There were several significant differences between VLBW and control parents' responses across a number of areas, which are summarized below. For some items trends were found in the expected direction which may have reached significance with a larger sample size, however it was encouraging to note that for many variables no such trends emerged. This suggests that VLBW young adults may experience similar outcomes to controls for many measures.

Health

Parents of VLBW young adults reported that their child experienced poorer health at a young age, as well as a greater mean number of health problems throughout the life course. VLBW young adults were more likely to be living with a significant physical disability at 27/28 years than controls and a greater proportion of VLBW young adults had been diagnosed with chronic wheeze/cough and certain bone/joint problems in their lifetime.

Of the additional comments made by parents about their child's health, poor airway/lung function was a common theme and was noted more frequently by VLBW parents than controls. Interestingly, across both groups more parental than self-reports described young adult health as fair/poor. 22.5% of VLBW parents felt their offspring's current health was fair/poor compared with 7.5% of the young adults themselves.

Education

Parents of the VLBW group reported a higher number of childhood academic difficulties than control parents. Mathematics in particular was a problem area, with half of all VLBW children experiencing some difficulties, compared to 20% of control children. VLBW children were more likely to be diagnosed with a learning difficulty than were controls (25% and 6.7% respectively) and a greater proportion received extra help/support with schoolwork, behaviour or other difficulties.

Behaviour and personality

VLBW parents scored their children more poorly than controls for several personality/behavioural traits: attention/concentration, social maturity/responsibility and leadership. When asked about risk-taking behaviours, VLBW young adults were found more likely to have been arrested than controls, although the NZ VLBW study found that at 22/23 years the VLBW group were less likely to have been arrested.

Social functioning

The quality of parent-child relationships was slightly lower in the VLBW group and parental over-control marginally higher, a trend that was consistent across parental and self-reports. VLBW young adults had fewer friends than controls (based on self and parental assessment) and were also less likely to be in a current romantic relationship. Parental reports suggest the VLBW group are more likely to experience difficulties forming partner attachments and may be delayed in doing so.

Physical fitness/co-ordination

VLBW young adults struggled more than controls with certain aspects of physical coordination (e.g. catching a ball). Interestingly, engagement in regular physical activity was rated similarly by parents across both groups, however based on young adult self-reports, the VLBW group are less likely to participate in regular exercise.

Quality of life/self esteem

Parents rated overall quality of life slightly lower for VLBW young adults, but scored them higher than controls for self-esteem. This differs from self-reports where self-esteem was found to be poorer in the VLBW group. VLBW individuals were also more likely to experience lower overall life-satisfaction, which was consistent across self and parental reports.

Conclusions:

Parental assessment of young adult health and functioning has highlighted a number of areas where VLBW young adults experience poorer outcomes than their non-VLBW counterparts. Further trends have been implied by the data which lack significance but are largely consistent with previous findings. It is encouraging to note that for many of the outcomes investigated, no differences were suggested between the two groups. The findings from this study, along with comments regarding study questions/protocols, will be useful in informing ongoing research in the area and a source of interest in the future.