

ORIGINAL ARTICLE

Prioritising long-term outcomes for preterm babies: A survey of consumers and clinicians

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Aim: To determine if consumers and clinicians believe intelligence or health outcomes are more important long-term outcomes for babies born preterm.

Methods: Prospective, online survey of six outcomes ranked using a hierarchy ladder, Likert scale and a hypothetical scenario: education (complete secondary school); longevity (70 years of age or more); money (sufficient for rent and food); normal weight; good health and intelligence. Participants were clinicians taking care of preterm babies, parents of preterm babies, ex-preterm adults and adult controls.

Results: The survey was completed by 145 participants (35 controls, 36 clinicians, 39 parents and 35 ex-preterm adults). Health was the most frequently top-ranked variable on the hierarchy ladder (health; 99/145 (68.3%), money; 17/145 (11.7%), longevity; 10/145 (6.9%), education; 8/145 (5.5%), normal weight; 6/145 (4.1%), intelligence; 5/145 (3.4%), $P < 0.0001$), with no statistical difference between the groups. On a 5-point Likert scale, participants were most likely to agree that sufficient money, health and finishing secondary school were important for preterm babies to have a good life (mean (SD): money 4.43 (0.81); health 4.39 (0.72); education 4.37 (0.81); normal weight 4.10 (0.81); intelligence 4.03 (0.94); longevity 4.01 (1.07), $P < 0.0001$). In the scenario, the option of an ex-preterm adult having a healthy life with low socio-economic status (SES), was preferred over high SES with an unhealthy life ($p < 0.0001$).

Conclusions: Health was perceived as the most important long-term outcome for preterm babies. Future research should prioritise good health outcomes for babies born preterm.

Key words: health; intelligence; preterm.

What is already known on this topic

- 1 Preterm babies are at increased risk of neurodevelopmental impairment, lower intelligence and poor cardiovascular outcomes.
- 2 Some neonatal interventions, such as increasing nutritional intake, may improve neurodevelopmental outcomes at the risk of worsening cardiovascular outcomes.
- 3 It is unknown whether clinicians and consumers, including ex-preterm adults, prioritise intelligence or health as outcomes for babies born preterm.

What this paper adds

- 1 Survey participants prioritised health over intelligence on a hierarchy ladder, Likert scale and hypothetical scenario.
- 2 Responses were similar between clinicians, parents, ex-preterm adults and controls.

Preterm birth (<37 weeks gestational age (GA)) is common, comprising approximately 11% of all live births.¹ With advances in neonatal care, survival of extremely preterm babies (<28 weeks

GA) has improved over time.² However, preterm babies continue to be at increased risk of adverse outcomes including neurodevelopmental impairment including developmental delay³ and intellectual disability⁴ and poorer health outcomes in adulthood such as diabetes⁵ cardiovascular disease⁶ and health related quality of life (HRQoL)⁷ than those born at term.

Enhanced neonatal nutrition in preterm children is associated with faster growth,⁸ and improved brain development and long-term cognitive function,⁹ with some data to show that preterm babies that receive more nutrition are more intelligent in later life,¹⁰ although more randomised trials are needed to confirm this finding. Intelligence can have an indirect positive influence

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on quality of life; people who are intelligent are more likely to achieve higher educational qualifications¹¹ and have higher life satisfaction.¹²

Although early accelerated postnatal growth may improve neurodevelopment, it may also predispose preterm babies to a higher risk of health complications.¹³ Therefore, it is important that any potentially advantageous effect of slower growth on long-term health are balanced against the adverse effects of undernutrition on the brain.

Our aim was to determine what consumers and clinicians overall believe are the most important long-term outcomes for babies born preterm.

Materials and Methods

This study was an online anonymous cross-sectional survey, using Survey Monkey software (SurveyMonkey, California, USA), with 40 questions (Supporting information) which were presented either on a computer tablet, or through an online link sent to participants' email. A convenience sample of participants were recruited from parents of preterm babies (Parents), clinicians working with preterm babies (Clinicians), Ex-preterm adults and Controls. Both Parents and Clinicians were identified in the neonatal intensive care unit and postnatal ward at Auckland City Hospital. Ex-preterm adults were recruited from participants from a previous study and from posters. Controls were adult visitors to the hospital (non-neonatal or obstetric) and were approached in public areas of the hospital. The accessibility of the survey was tested by nineteen volunteers prior to distribution. Participants were able to change their answers until they selected the "submit" button to enter their data. The study was approved by the Auckland Health Research Ethics Committee (000029) and the Auckland District Health Board (8103).

Participants

Inclusion criteria were Parents (either parent, but only one per family); Clinicians (doctors, nurses, midwives or dietitians caring for mothers and babies); Ex-preterm adults (born at <37 weeks GA) and Controls (not meeting any of the above criteria). Exclusion criteria were parents of preterm babies who had major congenital abnormalities, non-fluent English speakers and < 18 years of age. Eligible participants were provided with group-specific participation information sheets and informed consent was taken as given when participants selected the "submit button".

Variables

Six variables were assessed. Obesity, cardiovascular diseases and cardiometabolic risk factors are associated with a reduction in HRQoL,^{14,15} lower educational achievement increases the adverse effects of cardiometabolic conditions on HRQoL,¹⁶ and income is negatively associated with HRQoL.¹⁷ Therefore, to assess attitudes to long-term health participants were asked to rank weight (to not be overweight or obese as an adult); health (to not have an illness such as diabetes, stroke, or heart disease, until at least 70 years of age) and longevity (to live to at least 70 years of age), and to assess attitudes to intelligence participants were asked to rank education (finish secondary school);

money (to have enough money to pay for rent and food) and intelligence (having average or above intelligence).

Hierarchy ladder

Participants were asked to rank the variables in the order of importance they perceived was required for a preterm baby to have a good life. A ranking of 1 was equivalent to the most important factor for a preterm baby to have a good life, while a ranking of 6 was the least important.

Likert Scale

A Likert-based scale was provided for the participants to answer how strongly they agreed or disagreed on having one of the six variables being "very important" for the preterm baby to have a good life. The options were rated on a 5-point scale from strongly disagree to strongly agree.

Hypothetical scenario

Participants were given different possible outcomes at for a hypothetical preterm baby at 40 years of age. Potential outcomes for three of seven levels were shown (Table 1) with four additional options in between the three outcomes available to be selected. The range of outcomes varied from the ex-preterm adult has a lower socio-economic status (SES; lower paid job) but is healthy, at the other end he has a higher SES (higher paid job) but is less healthy, and in the middle has an average SES and health. Income values were based on the 2013 Census data for the 5th, median and the 95th percentiles of the full-time income (working at least 30 h a week) for men between 40 and 44 years old.¹⁸ The values were adjusted for the increase in salaries since 2013, using the Consumers Price Index from Q1 2013 to Q1 2018. The age of death was based on the 2018 StatsNZ data for the 5th, median and 95th percentiles of the distribution of death for men born in 1978 and still alive at 40 years old.

Data was also collected on participants general health using the 12-item-short-form health survey (SF-12-V2), including the physical and the mental component,¹⁹ a summary score for the subjective social status (MacArthur Scale)²⁰ and objective social status (personal and household income, highest qualification and current occupation).

Outcomes

The primary outcome was the top-ranked variable on the hierarchy ladder. The secondary outcomes were the importance of health and intelligence variables on a Likert scale and the hypothetical scenario.

Statistical analysis

To detect a difference in opinion from 50% to 75% of participants who believe that a health outcome is the highest option on the hierarchy ladder, with 80% power required 32 participants in each group. To allow for 10% of the participants not completing

Table 1 Hypothetical scenario possible outcomes

Participants were asked:

‘To find out which outcomes you believe are more important, we have made up some possible future outcomes in adulthood for a preterm baby. At one end of the scale, the ex-preterm adult has a lower socio-economic status (lower paid job) but is healthy, at the other end he has a higher socio-economic status (higher paid job) but is less healthy, and in the middle has an average socio-economic status and health.

There are lots of different outcomes that may happen in the future for preterm babies, as there are for all babies, born preterm or not. Currently, it is not possible for doctors looking after preterm babies to change which outcome is more likely. If it was possible to choose an outcome, which one would you choose? Harry is currently at 40 years of age and he is married with two children’

Lower SES, healthy	Average SES and health	High SES, less healthy
Harry left school at 16 and works as a labourer on a building site where he earns \$34 320 per year. He has a normal body weight, and low risk of diabetes/health complications. He lives to 99 years of age.	Harry finished high school and works as an accounting technician for a retail firm where he earns \$69 626 per year. He is overweight. He develops high blood pressure at 70, then has a stroke and dies at 75 years of age.	Harry finished university and works as an architect and earns \$170 653 per year. He is obese (very overweight). He develops diabetes when he is 50, then has a heart attack at 60 years of age. He lives to 63 years of age.

Income values were based on the New Zealand 2013 Census data for the 5th, median and the 95th percentiles of the full-time income (working at least 30 h a week) for men between 40 and 44 years old. The values were then adjusted for the increase in salaries since 2013, using the Consumers Price Index from Q1 2013 to Q1 2018. The age of death was based on the 2018 StatsNZ data for the 5th, median and 95th percentiles of the distribution of death for men born in 1978 and still alive at 40 years old.

the full survey, we aimed to recruit 35 participants in each group for a total of 140 participants.

Data were analysed using JMP 12.1.02015 (SAS Institute Inc., Cary, NC, USA). Data are presented as number (percent), median (interquartile range or mean (95% confidence interval (CI)) as appropriate. Frequency distribution was analysed by one-way chi-square compared to expected frequency (even distribution). Categorical data were analysed by chi-square with post hoc analysis by logistic regression. Non-parametric data continuous data with multiple groups were analysed by the Median test with Steel-Dwass All Pairs post hoc test. Parametric continuous data with multiple groups were analysed by ANOVA with Tukey All Pairs post hoc test. Priorities were described using a 5-point Likert scale and analysed as continuous variables.²¹ There were no missing data from completed surveys. A two-tailed *P* value of <0.05 was considered to be statistically significant.

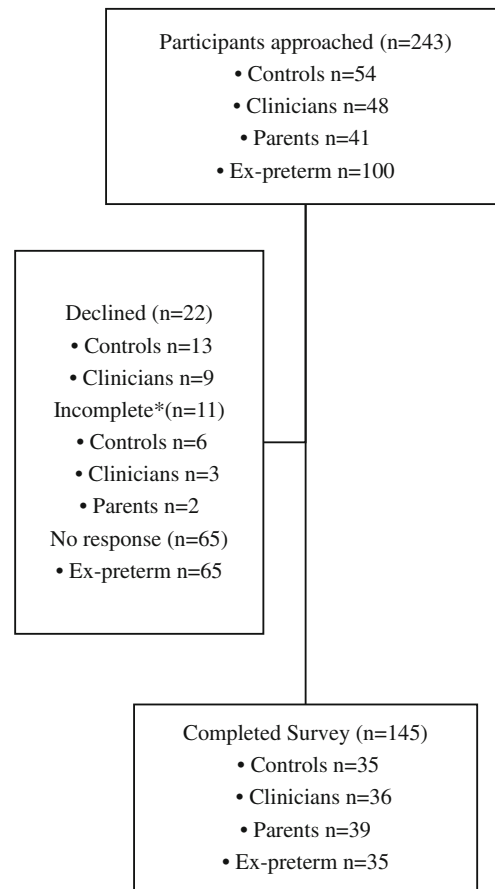


Fig. 1 STROBE diagram of recruitment. *Participants who did not complete the survey.

Results

There were 243 eligible adults approached and 145 (60%) completed the survey (Fig. 1) between July 2018 and March 2020. The majority of the participants were female and New Zealand European (Table 2).

Hierarchy ladder

The majority of participants ranked health at the top of the hierarchy ladder (Fig. 2), with only two participants (one Control and one Parent) ranking health as the least important variable. There were no statistically significant differences in what was perceived as the top-ranked variable between the groups with the majority of participants across all four groups ranking health as the top variable. Overall, longevity and normal weight were most frequently selected as the lowest-ranked variable with no statistical difference between the groups.

Health was less likely to be ranked as the most important variable if the participant was born preterm (preterm; 30/47(63.8%) versus not preterm 66/95 (69.5%), *P* = 0.04). Of those born preterm, health was as likely to be ranked as the most important variable by those who were born late preterm (34–36 weeks GA)

Table 2 Baseline characteristics

Variables	Total (n = 145)	Controls (n = 35)	Clinicians (n = 36)	Parents (n = 39)	Ex-preterm (n = 35)
Age (years)	36.0 (11.3)	36.0 (13.0)	39.4 (12.1)	31.4 (5.1)	37.7 (12.2)
Male	43 (29.7)	13 (37.1)	4 (11.1)	9 (34.6)	17 (48.6)
Ethnicity					
Māori	20 (13.8)	5 (14.3)	2 (5.6)	10 (25.6)	3 (8.6)
Pacific island	12 (8.3)	4 (11.4)	1 (2.8)	5 (12.8)	2 (5.7)
Asian	31 (21.4)	11 (31.4)	6 (16.7)	9 (23.1)	5 (14.3)
NZ European	66 (45.5)	10 (28.6)	21 (58.3)	12 (30.8)	23 (65.7)
Others	16 (11.0)	5 (14.3)	6 (16.7)	3 (7.7)	2 (5.7)
Height (cm)	168.5 (9.9)	167.8 (11.0)	166.6 (6.8)	168.2 (10.8)	171.5 (10.3)
Weight (kg)	76.8 (22.4)	78.1 (25.0)	67.0 (16.0)	80.8 (22.3)	81.2 (23.3)
BMI (kg/m ²)	27.0 (7.1)	27.4 (6.9)	24.1 (5.6)	28.4 (6.7)	28.0 (8.5)
Participant born preterm	47 (33.1)	0 (0)	2 (5.9)	10 (27.0)	35 (100.0)
Participant GA at birth					
37 weeks or above	95 (65.5)	35 (100)	33 (91.7)	27 (69.2)	0 (0)
34–36 weeks	22 (15.2)	0 (0)	1 (2.8)	2 (5.1)	19 (54.3)
32–33 weeks	8 (5.5)	0 (0)	0 (0)	2 (5.1)	6 (17.1)
28–31 weeks	9 (6.2)	0 (0)	1 (2.8)	3 (7.7)	5 (14.3)
Less than 28 weeks	4 (2.8)	0 (0)	0 (0)	2 (5.1)	2 (5.7)
Do not know but preterm	4 (2.8)	0 (0)	0 (0)	1 (2.6)	3 (8.6)
Do not know at all	3 (2.1)	0 (0)	1 (2.8)	2 (5.1)	0 (0)
Parent participant's child GA at birth					
34–36 weeks				10 (25.6)	
32–33 weeks				10 (25.6)	
28–31 weeks				15 (38.5)	
Less than 28 weeks				4 (10.2)	
Summary PCS score	52 (46–56)	48 (44–55)	56 (51–57)	47 (37–52)	53 (51–57) †
Summary MCS score	49 (45–52)	49 (44–52)	50 (48–53)	46 (41–50)	50 (46–53)
Subjective social status	7.0 (1.5)	7.1 (1.2)	7.6 (1.6)	6.9 (1.8)	6.4 (1.3)
Serious health problem	33 (22.8)	8 (22.9)	9 (25.0)	5 (12.8)	11 (31.4)
Specific health problem					
Diabetes	6 (18.2)	3 (37.5)	0 (0)	1 (20.0)	2 (18.2)
Stroke	0 (0)	0 (0)	0 (0)	0 (0)	0 (0)
Heart disease	1 (3.0)	0 (0)	0 (0)	0 (0)	1 (9.1)
Cancer	2 (6.1)	0 (0)	0 (0)	0 (0)	2 (18.2)
Hypertension	13 (39.4)	3 (37.5)	5 (55.6)	2 (40.0)	3 (27.3)
Asthma	4 (12.1)	0 (0)	4 (44.4)	0 (0)	0 (0)
Others ‡	7 (21.2)	2 (25.0)	0 (0)	2 (40.0)	3 (27.3)
Education					
No formal education	2 (1.4)	0 (0)	0 (0)	2 (5.1)	0 (0)
Secondary school	22 (15.2)	6 (17.1)	0 (0)	8 (20.5)	8 (22.2)
Tertiary education	81 (55.9)	22 (62.9)	17 (47.2)	22 (56.4)	20 (57.1)
Postgraduate degree	40 (27.6)	7 (20.0)	19 (52.8)	7 (17.9)	7 (19.4)
Personal income (per annum)					
<\$30 000	39 (26.9)	12 (34.3)	2 (5.6)	13 (33.3)	12 (34.3)
\$30 001–\$60 000	33 (22.8)	11 (31.4)	3 (8.3)	12 (30.8)	7 (20.0)
\$60 001–\$100 000	44 (30.3)	8 (22.9)	16 (44.4)	11 (28.2)	9 (25.7)
\$100 001 or more	29 (20.0)	4 (11.4)	15 (41.7)	3 (7.7)	7 (20.0)
Occupation					
Unemployed	10 (6.9)	2 (5.7)	0 (0)	8 (20.5)	0 (0)
Blue collar worker	11 (7.6)	7 (20.0)	0 (0)	2 (5.1)	2 (5.1)
White collar	27 (18.6)	7 (20.0)	0 (0)	10 (25.6)	10 (28.6)
Professional	74 (51.0)	12 (34.3)	34 (94.4)	15 (38.5)	13 (37.1)

(Continues)

Table 2 (Continued)

Variables	Total (n = 145)	Controls (n = 35)	Clinicians (n = 36)	Parents (n = 39)	Ex-preterm (n = 35)
Student	20 (13.8)	6 (17.1)	2 (5.6)	2 (5.1)	10 (28.6)
Unpaid caregiver	3 (2.1)	1 (2.9)	0 (0)	2 (5.1)	0 (0)

BMI, body mass index, born preterm: born before 37 weeks of gestational age. MCS, Mental Component Summary. PCS, Physical Component Summary. Income is defined as annual earnings, before tax. Blue collar workers defined as jobs that require manual labour; white workers defined as jobs in office or other administrative setting. Data are presented as number (%), mean (SD) or median (IQR). The number of participants in each group with a serious health problem was used as the denominator for the specific health problem. † Includes pancreatitis, ankylosing spondylitis, pre-eclampsia, rheumatoid arthritis, Cushing syndrome and rheumatic fever.

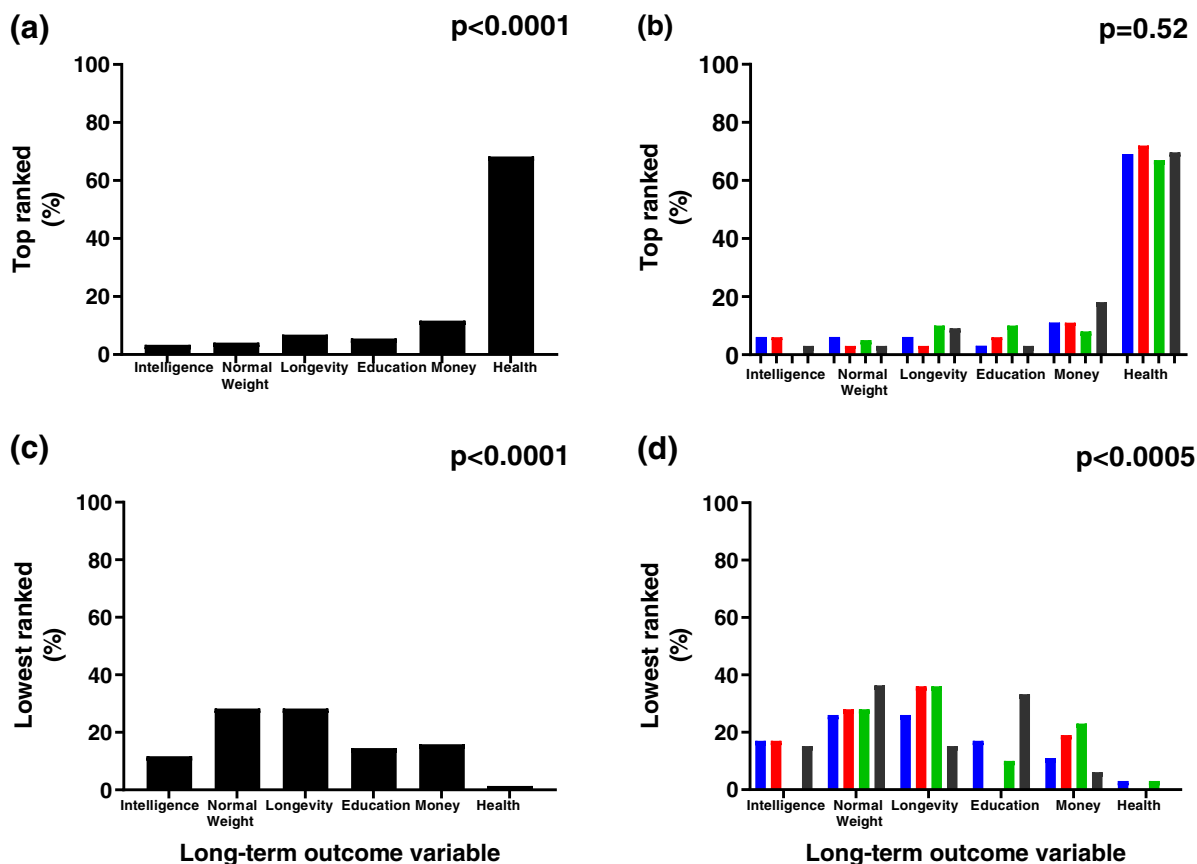


Fig. 2 Perceived ranking of long-term health and socio-economic variables. The percentage of top ranked (a), top ranked by groups (b), lowest ranked (c) and lowest ranked by groups (d) of the perceived relative importance of long-term health and intelligent variables for people born preterm. Participants were asked on a scale of 1–6 (1 = most important, 6 = least important), to rank the following health or intelligent variables in order of the importance they believed to allow baby born preterm to have a good life in adulthood: to live to at least 70 years of age (longevity); to have enough money to pay for rent and food (money); to not be overweight or obese as an adult (weight); to not have an illness such as diabetes, stroke, or heart disease, until at least 70 years of age (health); to finish secondary school (education); to be having average or above intelligence (intelligence). Data are represented as percentages of the total number of participants. For (a and b), *P* values represent statistical differences between the frequency of long-term outcome variables ranked by the participants against an expected even distribution. For (c and d), *P* values represent statistical differences between the Controls (blue), Clinicians (red), Parents (green) and Ex-preterm (black).

as those who were moderate/very or extremely preterm (<34 weeks), (34–36 weeks GA, 14/22 (63%) *v* < 34 weeks GA, 13/21 (62%), *P* = 0.28). There was no effect of age (*P* = 0.24),

gender (*P* = 0.22) or BMI (*P* = 0.72). After adjustment for age, gender, BMI and preterm birth, there was no difference on the highest-ranked variable between the participant groups

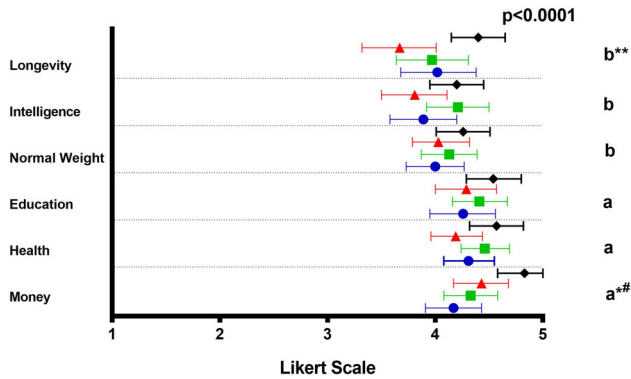


Fig. 3 Perceived importance of long-term health and intelligence variables for people born preterm among consumers and clinicians. Participants were asked on a scale of 1–5 (1 = strongly disagree, 5 = strongly agree) whether they believed it was very important for a person born preterm to have the following outcomes when they reached adulthood or not: to finish secondary school (education), to live to at least 70 years of age (longevity); to have enough money to pay for rent and food (money); to not be overweight or obese (normal weight); to not having an illness such as diabetes, stroke, or heart disease, until at least 70 years of age (health); and to be having average or above intelligence (intelligence). Data are represented as mean (95% confidence interval). Circles; Controls ($n = 35$), triangles; Clinicians ($n = 36$), squares; Parents ($n = 39$), diamonds; and Ex-preterm ($n = 35$). Significant difference ($P < 0.05$) in perceived best outcome for babies born preterm across all respondents is indicated by non-matching letters. Symbols indicate significant difference between clinical disciplines for each outcome: Ex-preterm compared with Clinicians; * ($P < 0.05$), and Parents; ** ($P < 0.01$); Ex-preterm compared with Parents; # ($P < 0.005$).

($P = 0.07$). There was no statistical association between the ranking score on the hierarchy ladder and participant’s health status (Physical component score ($P = 0.51$), mental component score ($P = 0.38$), subjective SES ($p = 0.78$) or objective SES (education (0.18), personal income ($P = 0.49$) and occupation ($P = 0.64$)).

Likert scale

Education, health and money were perceived to be the most important long-term outcome for babies born preterm on the Likert Scale (Fig. 3), while longevity, weight and intelligence were perceived to be of less importance. The Ex-preterm group perceived longevity to be a more important long-term outcome than Clinicians, and money to be more important than Clinicians and Controls.

Hypothetical scenario

Participants were more likely to select outcomes tending towards higher health but lower SES, than outcomes with higher SES but less healthy (Fig. 4). The most frequently chosen outcome was the option of a normal body weight, health, longest life-span and lowest financial income (50/145 (34.5%)). Only a few participants (10/145 (6.9%)) selected the outcome with the worst health, shortest life-span and highest SES. There was no significant difference between participant groups and their preferred

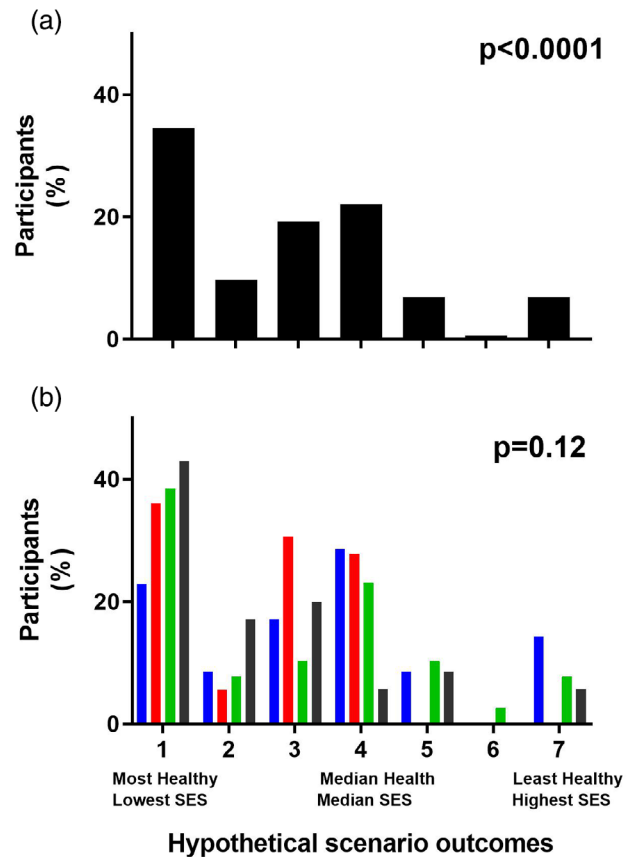


Fig. 4 Hypothetical scenario outcome. Participants were presented with a hypothetical scenario consisting of seven possible long-term outcomes for a preterm baby, ranging from most healthy and lowest SES to the least healthy and highest SES outcome, and asked to select one outcome. A represents the total response; B represents the response by groups represented by Controls (blue), Clinicians (red), Parents (green) and Ex-preterm (black). Data are represented as n (%). For (a), P values represent statistical differences between the long-term outcome chosen by participants against an expected even distribution. For (b), P values represent statistical differences between the participant group.

outcome on the hypothetical scenario. In the comments field, eight participants mentioned the importance of happiness and that it may have influenced their choice if it had been included in the scenario.

Discussion

We investigated what consumers and clinicians believe are the most important long-term outcome for preterm babies. Health was consistently ranked in the hierarchy ladder, the Likert scale and the hypothetical scenario as the most important factor for preterm babies to have a good life, with no perceived difference between the participant groups. Intelligence was the least common item to be ranked the most important variable on the hierarchy ladder, and perceived as the least important variable on the Likert scale.

Multiple perinatal interventions may have opposing effects on neurodevelopment and health. Neonatal nutrition is essential for post-natal growth in babies born preterm but rapid growth may have opposing effects on later health and intelligence.²² Treatments such as antenatal corticosteroids for accelerating fetal lung maturation in women at risk of preterm birth of respiratory distress syndrome reduce intraventricular haemorrhage and developmental delay,²³ but may also increase insulin resistance,²⁴ potentially increasing the risk of diabetes in later life. Clinicians caring for preterm babies should balance the impact of interventions in the newborn period on long-term neurodevelopment and health when deciding to use these interventions. The results of this survey indicate that health is preferred as a long-term outcome over intelligence, suggesting that clinicians should discuss the potential impact of perinatal interventions on both long-term health and intelligence with parents of preterm babies.

Both ex-very preterm adults and their parents report that they have a lower health-related quality of life than term born controls, but in contrast to their children's perception parents perceived that their children's health-related quality of life worsened between adolescence and adulthood.¹⁷ In contrast to our results, a survey by Jaworski et al. found parents were more than twice as likely to be concerned about their child's development than their physical health,²⁵ with almost half of the parents with children showing no signs of neurodevelopmental impairment still expressing concerns with their future development. This may be explained by a few differences between the studies including the eligibility criteria for parents (baby born less than 29 weeks GA vs. less than 37 weeks GA), the stage in their preterm child's development when the parents were surveyed (on the post-natal wards vs. at 18 months), and the focus of outcome (immediate vs. long-term) for the preterm child. Nevertheless, these differences may suggest that parental perception of a 'good outcome' may differ depending on the degree of prematurity, stage of development and the child's current development.

There were differences in baseline characteristics between participant groups, with Clinicians being older, having a lower weight and BMI, less likely to have been born preterm. These differences may have had an influence on participants' beliefs. Older age is generally associated with greater burden of disease and greater health loss, while obesity is associated with multiple debilitating health complications and a reduced quality of life.¹⁵ However, after adjustment for the factors mentioned above, no statistical difference was found between the groups with health remaining the top-ranked variable, making it unlikely that the baseline characteristics between the groups affected the outcomes of the study.

During the neonatal period, mothers of preterm babies can have more psychosocial distress than mothers of term babies, which may continue beyond the neonatal period.²⁶ To alleviate possible parental distress as much as possible, parents in our survey were approached near the end of their NICU stay, when the stress levels were likely to be lower compared to their initial hospitalisation. However, there is some evidence that parents experience stress for the duration of a preterm baby's admission in the NICU, independent of the baby's health as perceived by clinicians.²⁷ Stress may therefore influence parents to prioritise health as the most important long-term outcome.

Previously, happiness has been shown to be viewed as an important long-term outcome.²⁵ We did not include happiness as a variable as the purpose of the scenario was for the participants to evaluate the overall state of the hypothetical individual (determining for themselves whether the health and socio-economic alternatives would contribute to happiness) and select what the participants believed was the best possible outcome. Future research could include qualitative methods to determine if happiness is an important outcome for those born preterm.

There are several limitations to this study, including potential bias as this was a sample of convenience limited to English-speaking participants and as the control group were visitors to the hospital, they will know someone with poor health. The majority of ex-preterm participants were born late preterm with few participants being born extremely preterm, which is the group most likely to have neurodevelopmental impairment. In addition, intelligence and health outcomes may be interrelated with respect to health literacy and life-style choices. There may be ethnic differences in beliefs on the importance of long-term outcomes of preterm babies, which we were not able to analyse due to low numbers of Māori participants. Furthermore, the findings may not be generalisable as this is a single hospital study, the response rate was 60%, and while these findings may be representative of the views of non-Māori people in Aotearoa New Zealand and other developed countries, they may not be valid in less developed countries.

Conclusions

Health was perceived as a more important long-term outcome than intelligence for babies born preterm. Future research should include long-term health outcomes as well as cognitive outcomes for babies born preterm. Clinicians should discuss the potential impact of perinatal interventions on both long-term health and intelligence with parents of preterm babies.

Acknowledgement

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Ethics Statement

The study was approved by the Auckland Health Research Ethics Committee (000029) and the Auckland District Health Board (8103). All participants gave informed consent. The Ethics committee agreed that consent was taken as participant's pushed the 'Submit' button at the end of the survey.

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Supporting Information

Additional Supporting Information may be found in the online version of this article at the publisher's web-site:

Appendix S1. Supporting Information