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Racial disparities in health-related quality of life in a cohort of very low birthweight 2- and 3-year-olds with and without cerebral palsy

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Abstract

We examine racial differences in health-related quality of life (HRQoL) among 2- and 3-year-olds born very low birthweight (VLBW, <1500g). The sample included 611 children (290 males and 321 females) from the Newborn Lung Project, a cohort of VLBW infants hospitalized in Wisconsin's newborn intensive care units during 2003 to 2004. Of the 611 children, 14% (86/611) were black, non-Hispanic and 86% (525/611) were white, non-Hispanic and 4% (23/611) had cerebral palsy. HRQoL was measured using the Pediatric Quality of Life Inventory. Black children scored nearly 4 points lower (mean difference -3.6, 95% confidence interval [CI]: -6.9 to -0.3) on HRQoL than their white peers. Cerebral palsy is associated with lower HRQoL (mean difference -24.4, 95% CI: -29.3 to -19.5), especially among black children, but does not explain racial differences in HRQoL. Living in a neighborhood with lowest levels of female education is associated with lower HRQoL (mean difference -5.6, 95% CI: -9.2 to -2.1), but does not explain the racial difference in HRQoL.

What this paper adds

- Black, non-Hispanic very low birthweight 2- and 3-year-olds demonstrate lower HRQoL than their white, non-Hispanic counterparts, and black children with CP are particularly affected.
- Child socio-economic characteristics, functional limitations, and neighborhood context, although predictors of HRQoL, do not explain observed racial differences in HRQoL.

Cerebral palsy (CP) is one of the most serious consequences of very low birthweight (VLBW, <1500g). The prevalence of CP is 7 to 12% among VLBW infants¹ with black, non-Hispanic children, and children living in poorer areas most affected.²

Health-related quality of life (HRQoL) is increasingly recognized as a metric to assess health and well-being of children with developmental difficulties.³ HRQoL is represented by a single, summary measure of physical, emotional, and social health. Low HRQoL among young children born VLBW and those with CP has been well established.^{4,5}

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In the United States, black, non-Hispanic VLBW children may be more likely to have low HRQoL for a number of reasons, including their higher risk for CP. Moreover, black VLBW children may experience CP differently than their white counterparts. For example, adverse family socio-demographic characteristics and psychosocial processes predict lower HRQoL⁶ above and beyond neurological severity, and black children disproportionately live in families with social disadvantage.⁷

Maternal education is one of the most important family-level socio-economic predictors of outcomes among children with CP.⁸ Parallel to the importance of maternal education on the individual level, the education level of women (many of whom are mothers) in the neighborhood may cumulatively affect families' opportunities for knowledge, resources, and avenues for advocacy. Hence, it serves as a proxy for opportunities for the child that enhance or detract from those generated by the education level of the child's own mother.

The aims of this study are to (1) describe racial differences in HRQoL among 2- and 3-year-olds born VLBW, and (2) examine whether CP and neighborhood female education explain racial differences in HRQoL.

METHODS

Study population

Study children were from the Newborn Lung Project, a regional cohort of infants born VLBW in 2003 to 2004 and hospitalized in one of 16 newborn intensive care units (NICU) in Wisconsin or one near the state border. The original study recruited 852 white and black infants, alive at NICU discharge, for whom parents provided follow-up contact information. At age 2 to 3 years, 14 had died and 35 were lost. Of the remaining 803, 135 did not respond and 21 refused, leaving the parents of 647 with interview data when the child was between the ages of 2 years and 3 years 7 months. Neonatal characteristics predictive of CP for children with parent interviews were very similar to those of all survivors. Data for 36 children were omitted due to missing information on variables important to the present analysis. Sensitivity analyses including these latter cases with missing data did not notably change estimates so we restrict our analyses to children ($n=611$) with complete data. In sensitivity analyses using neonatal measures of medical and socio-demographic risk, we found no evidence of bias introduced by differential follow-up.

Outcome measure

Children's HRQoL was measured using the Pediatric Quality of Life Inventory⁹ reported by parents for toddlers ages 2 to 4 years (PedsQL). The PedsQL contains 21 items in four domains: physical, emotional, social, and school/daycare. Parents rate, on a 5-point scale (0=never a problem to 4=almost always a problem), their perception, in the last month, of how difficult each task was for their child to complete. A total score (range 0–100) reflects the summation of reverse coded responses. Higher scores indicate higher HRQoL. The PedsQL discriminates between children with and without chronic conditions and has a Cronbach's alpha of 0.70.¹⁰

Primary covariates

Cerebral palsy was collected via parent report. Parent-reported CP was consistent with functional mobility difficulties (i.e. >2SD below the mean) as measured by the Pediatric Evaluation of Disability Inventory (Table I). Neighborhood female education, operationalized by the child's resident census tract (CT), was measured by the percent of females with at least a bachelor's degree. We classify this as low (<5%; in the lowest

quartile), middle ($\geq 5\%$ and $< 20\%$; in the middle two quartiles) and high ($\geq 20\%$; in the highest quartile; Table I).

Analyses

Our cross-sectional analysis estimated associations using a mixed linear regression model with random intercept. This allows adjustment for non-independence arising from children in the same neighborhood sharing characteristics beyond those explicitly modeled.¹¹

The first model examined racial difference in HRQoL, adjusting for children's medical and socio-demographic characteristics. The second model added CP, and the third an interaction term between child's race and CP. The fourth model added motor and social function, and the fifth neighborhood female education. All continuous variables were centered at their means. For each model, we report the estimated mean change in HRQoL and its 95% confidence interval for each covariate as well as measure of model fit (i.e. $-2 \log$ likelihood).

All analyses were conducted in SAS v9.2 by PROC MIXED (SAS Institute Inc., Cary, NC, USA). The Institutional Review Boards at University of Wisconsin-Madison and all participating sites approved this study. Parents of the study children provided written informed consent to participate.

RESULTS

The multi-level analyses (Table SI, supporting material published online) included 415 neighborhoods. In Model 1, we find that black children had nearly 4-point lower HRQoL than white children, above and beyond other neonatal health and socio-demographic covariates (mean difference -3.6 , 95% CI: -6.9 to -0.3).

Model 2 shows that children with CP had 24-point lower HRQoL (mean difference -24.4 , 95% CI: -29.3 to -19.5) than those without CP, above and beyond neonatal health and socio-demographic covariates.

In Model 2, the racial difference in HRQoL remained unchanged from Model 1 and (mean difference -4.0 , 95% CI: -7.1 to -0.9) indicating no evidence that lower HRQoL among black children was due to their greater likelihood of having CP.

Model 3 shows that the association between CP and HRQoL was stronger for black children. That is, the interaction term between CP and black race suggests that among children with CP, black children have 31.2-point lower HRQoL than white children ($p < .01$).

Addition of the social and motor function reduced but did not eliminate the effects of black race, CP, and the interaction between black race and CP (mean difference -17.6 , 95% CI: -26.9 to -8.3).

Model 5 indicates that children living in neighborhoods with the lowest level of female education had a nearly 6-point lower HRQoL (mean difference -5.6 , 95% CI: -9.2 to -2.1) even after controlling for CP, child socio-demographic characteristics, and social and motor function. There was no evidence that neighborhood female education explained lower HRQoL among black children with CP. The interaction between black race and CP remained (mean difference -18.1 , 95% CI: -27.3 to -8.8 in Model 5) when neighborhood female education was included.

DISCUSSION

Among 2- and 3-year-olds born VLBW, we find that black children experience lower HRQoL than their white peers, and racial disparities in HRQoL are not explained by medical, socio-demographic, or neighborhood variables either overall or among children with CP.

Parent-reported HRQoL may capture not only dimensions of the child's health and well-being, but also parents' adaptation to their child's health condition. Research suggests that parent-proxy HRQoL is influenced by both parental socio-demographic characteristics and children's illness severity and is most concordant with child reports for physical health.¹² Our findings are consistent with previous literature suggesting HRQoL and functional skills are overlapping but separate constructs,¹³ where HRQoL captures not only aspects of function, but also problems generated in the child's interaction with his or her surroundings. Therefore, our finding of disproportionately lower HRQoL in black children with CP has important clinical implications for promoting opportunities for social participation, engagement, and inclusion.

We find that children living in neighborhoods with the lowest level of female education, likely an indicator for social and developmental disadvantage, have lower HRQoL than their peers living in more advantaged neighborhoods. While black children are more likely to live in such neighborhoods, this does not explain racial disparities in HRQoL among children with or without CP.

We acknowledge several limitations to this study. It is cross-sectional, so we cannot ascribe causality to associations between race, CP, neighborhood-level female education, and HRQoL. Biases introduced by unobserved characteristics may have affected our findings. Moreover, there is no criterion standard for measuring HRQoL in children. While many pediatric HRQoL measurements exist, a recent review suggests that PedsQL has excellent reliability and is easily administered.¹⁰

About one-third of the original cohort was lost to follow-up and more black than white children were lost. However, neonatal characteristics for both black and white children followed were almost identical to those of all NICU survivors. Indeed, if the black children followed differed on unmeasured covariates from those not followed, we may actually underestimate racial differences in HRQoL, as black children not followed likely have worse medical and social characteristics. Finally, relying on parent-reported CP may introduce bias if black children are more or less likely to receive a CP diagnosis. Our prevalence estimates (both overall and race-specific) match national data. However, this only suggests that any potential access to care biases are no worse in this regional cohort than in a larger cross-section of the country.

In light of increases in both births and survival of VLBW infants, the implication of neurodevelopmental vulnerability generally and racial differences in HRQoL specifically is of particular concern and should be the focus of future study.

Supplementary Material

Refer to Web version on PubMed Central for supplementary material.

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Table I

Medical and socio-demographic characteristics of the study cohort ($n=611$) by race, of very low birth weight 2- and 3-year-olds in Wisconsin

Characteristic	Black, $n=86$	White, $n=525$
Total annual income, US\$	<i>n</i> (%)	
Less than 10 000	57 (66.3)	53 (10.1)
10 000 – 30 000	14 (16.3)	95 (18.1)
30,000 – 60 000	10 (11.6)	154 (29.3)
More than 60 000	5 (5.8)	223 (42.8)
Parental education		
Less than a high school (HS) degree	22 (25.6)	12 (2.3)
HS degree or equivalent	30 (34.9)	99 (18.9)
Some post HS schooling	23 (26.7)	202 (38.5)
Bachelor's degree or post graduate studies	11 (12.8)	212 (40.4)
Sex of the child		
Male	43 (50.0)	247 (47.1)
Female	43 (50.0)	278 (53.0)
Child has cerebral palsy ^a	6 (7.3)	17 (3.3)
Mother smoked during pregnancy	27 (31.4)	77 (14.7)
Child currently lives with a smoker	11 (12.8)	20 (3.8)
Child lives with single biological parent	62 (72.1)	78 (14.9)
Child attends daycare	37 (43.0)	219 (41.7)
Mother received no prenatal care	8 (9.30)	6 (1.1)
Category of neighborhood female education ^b		
Low (<5%)	27 (31.40)	32 (6.0)
Middle (≥5% and <20%)	50 (58.1)	384 (73.1)
High (≥20%)	9 (10.5)	109 (20.8)
	Mean (SD)	
Birth weight, g	1044 (282)	1093 (279)
Gestational age, wks	28 (2.9)	28 (2.7)
Neonatal morbidity ^c	19.8 (14.4)	14.3 (12.8)
Health-related quality of life ^d	82.3 (17.2)	88.1 (11.5)
Child functional skills ^e		
Social function	38.8 (13.8)	48.0 (13.1)
Motor function	43.9 (15.2)	43.9 (12.5)

^aCollected via parent-report.

^b% of children living in each neighborhood category grouped according to the percentage of females with at least a Bachelor's degree.

^cNeonatal morbidity is measured using the SNAP-II (range 0–115), higher score indicates more severe morbidity.

^d Health-related quality of life (HRQoL), measured using the Pediatric Quality of Life Inventory, scores range from 0–100; higher scores indicate higher HRQoL.

^e Children's functional skills are measured using the Pediatric Evaluation of Disability Inventory (PEDI), which is normalized to have a mean of 50 and standard deviation of 10. The PEDI was administered in Wisconsin.