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Very low birth weight infants after discharge: What do parents describe?

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ABSTRACT

Background: Morbidity and mortality in Very Low Birth Weight (VLBW) infants during their hospital stay have been well described. However, there are insufficient data regarding health problems after discharge. *Study design:* In a multicenter study performed between January 2009 and December 2010 including 2493 VLBW infants, questionnaires were sent out to all participating parents in the first year of life. We compared the parental reported health of VLBW infants with a national cohort (KIGGS).

Results: The reported health of VLBW infants born after 29 weeks of gestation was identical to term infants. Even in the group of infants born before 24 weeks of gestation health was regarded as very good or good in >70% of cases. However, parents described a delayed development in >50% increasing to >70% with lower gestational age. In the first year of life VLBW infants have an increased risk of visual and hearing problems. Bronchitis was more frequent in VLBW infants but there were no differences in other infections typical for that age group. VLBW infants had less sleeping problems. No gender differences were described.

Conclusion: VLBW infants in our study require slightly more medical care compared to their peers. However, medical problems are relatively small compared to the developmental needs as perceived by their parents. Therefore, close follow-up and advice by specialists in infant development are needed.

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1. Introduction

Morbidity of very low birth weight infants (VLBW) is well described until discharge. However, problems after discharge during the first year of life have not been characterized in a larger cohort. Ten years ago Jackson et al. [1] described the utilization of the health care system by VLBW infants (N = 36) in Sweden. They demonstrated a nearly 3-fold increase in contacts with healthcare providers.

Twenty years ago van Zeben-van der Aa et al. [2] showed that 31% of VLBW infants (N=998) received physical therapy and 67% attended medical professionals other than their pediatrician. Use of health care services depended on the developmental outcome of the child.

Traditionally, former VLBW infants are supposed to suffer more severe respiratory infections. Harding and Howie [3] compared infants in Auckland to Newborn intensive care unit (NICU) survivors. While 8.6% of infants who were never admitted to a NICU had to be admitted to a hospital during their first year of life, this rate doubled in former VLBW infants (15.5%). Admissions were largely for respiratory infections. Since the introduction of Palivizumab as a prophylaxis for respiratory syncytial virus infection in at risk VLBW infants, rates of hospitalization after discharge have decreased. However, recently Miller et al. [4] showed that human rhinovirus is the predominant pathogen of the respiratory infections in premature infants in Argentina. Hagen et al. [5] demonstrated that former VLBW infants attending day care had an increased risk of respiratory problems and that bronchopulmonary dysplasia (BPD) and day care attendance increased the risk of respiratory infections but did not act synergistically. The increase in risk was similar to that of term children with one parent with a history of allergy/asthma.

Between 2003 and 2006 a large health survey was conducted in Germany. The KIGGS-study (Deutscher Kinder-und Jugendgesundheitssurvey) described a nationwide representative cohort of infants [6]. The aim of our analysis was to compare the parental report of the KIGGS cohort and VLBW infants with regard to medical care (acute and chronic health problems, therapies and prescriptions) and development in the first year of life.

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2. Material and methods

2.1. Participants

Data from VLBW infants born between 22 + 0 and 36 + 6 weeks of gestation and a birth weight of less than 1500 g were collected from 28 centers in Germany. Between 2009 and 2010 a total of 2493 VLBW infants were included in our study. The proper assessment of clinical data was ensured by on-site-monitoring. All parents received the KIGGS survey (1–2 years) in the first year of life.

For the comparison group we selected infants of 6 to 12 months of age (n=935) from a representative cross-sectional German health survey (KIGGS) conducted between 2003 and 2006.

2.2. Definitions

Bronchopulmonary dysplasia (BPD) was defined as the need for supplemental oxygen at 36 weeks postmenstrual age, including moderate and severe BPD according to the NIH definition. Intraventricular hemorrhage (IVH) was per definition any bleeding into the cerebral germinal matrix or the ventricles. Surgery for retinopathy of prematurity (ROP) was defined as any ROP treated with laser- or cryocoagulation. Surgery for NEC/FIP was defined as any surgery necessary for intestinal perforation or necrotizing enterocolitis; surgery for PDA was any surgical ligation for persistent ductus arteriosus.

The group of children with no adverse events did not suffer from any of the typical complications of prematurity (i.e. no surgery for NEC/FIP/PDA/ROP, no IVH grade 3 or 4).

2.3. Statistical analyses

The results from continuous and categorical variables are reported using quartiles and absolute and relative frequencies, respectively. To compare VLBW infants with children from KIGGS, groups were compared using the exact test by Fisher for categorical and Mann– Whitney U-test for continuous variables, respectively. To account for multiple testing, p values were adjusted using the procedure by Simes [7]. For further comparisons, descriptive two-sided p values are reported.

2.4. Ethics

The study was approved by the local committee on research in human subjects of the University of Luebeck, and the local committees of all participating centers.

Written informed parental consent was given for the research and publication of the results of each infant that was included in the study.

3. Results

Of the participating 2493 infants 2408 (97%) were discharged from hospital and 2383 were contacted by questionnaire. 1577 parents answered the questionnaire. The group of children with completed questionnaires is comparable regarding the incidence of surgery for PDA, IVH grade 3 or 4, PVL, to the whole group of VLBW infants included in the study. We noted an increased incidence in surgery for ROP (32/815 (3.9%) vs. 33/1556 (2.1%)) or NEC/FIP (52/822 (6.3%) vs. 48/1568 (3.1%)), BPD (154/825 (18.7%) vs. 230/1575 (14.6%)), a lower gestational age (median Q1/Q3: 28.4 (26.6/30.4) vs. 29.0 (26.9/30.9)) and birth weight (median in g Q1/Q3: 1065 (800/1300) vs. 1110 (850/1350)) in the group that did not answer the questionnaire. There were no differences regarding maternal or paternal education or monthly family income. Mothers who were not native Germans were less likely to answer the questionnaire (279/649 (43%) vs. 1298/1734 (71%)).

Comparing those infants with completed questionnaires and the KIGGS cohort, there were no differences regarding nationality (mothers nationality as German: VLBW 1374/1528 (90%) vs. KIGGS 834/930 (90%)) or German as the main language spoken at home (VLBW 1488/1544 (96%) vs. KIGGS 891/930 (96%)).

Differences between the VLBW infants and KIGGS cohort are summarized in Table 1. As expected, the VLBW infants required more resources from the health system than the controls. They are seen more often by their primary care physician (mostly a pediatrician in Germany) and ophthalmologist. All the VLBW infants have been to a pediatrician, while 2.2% of the KIGGS cohort has been seen exclusively by family doctors. VLBW infants are more at risk of developing bronchitis, but not a common cold. The frequency of consultations was

Table 1

Health problems/utilization of health system of VLBW infants compared to a national cohort.

	VLBW	KIGGS-group	р	Adj p
	N=1577	N=935		
Gestational age in weeks	29 (27-31)	39 (38-40)		
Birth weight in g	1110 (850-1350)	3400 (3032-3740)		
Male sex	798 (51.3)	480 (51.3)	1.0000	1.0000
Age at questionnaire in months	8.9 (8.1-9.9)	7.5 (5.2–9.7)		
Age at questionnaire in months, corrected for prematurity	6.4 (5.4-7.5)	7.5 (5.2–9.7)		
Consultation of physician during last month	1240/1532 (80.9%)	623/921 (67.6%)	1.93E-13	4.41E-13
No. of visits to pediatrician last 12 months	6 [4-10]	5 [4–7]	7.84E-23	2.51E-22
Ophthalmologist	985/1544 (63.8%)	73/927 (7.9%)	1.24E-184	1.98E - 183
Common cold	999/1429 (69.9%)	610/892 (68.4%)	0.4592	0.4900
Bronchitis	308/1228 (25.1%)	132/889 (14.8%)	7.75E-9	1.55E-08
Taking prescript medication	371/1551 (23.9%)	173/896 (19.3%)	0.0087	0.0127
Hearing problems	18/1577 (1.1%)	3/935 (0.3%)	0.0387	0.0442
Hearing aids	8/1577 (0.5%)	0/935 (0.0%)	0.0292	0.0359
Lenses	23/1577 (1.5%)	4/935 (0.4%)	0.0155	0.0207
Sleep disturbances	222/1475 (15.1%)	196/882 (22.1%)	1.33E-5	2.13E-05
More medical/social care compared to peers	363/1537 (23.6%)	27/895 (3.0%)	3.93E-49	3.14E-48
Treatment for developmental/behavioral problems	157/1485 (10.6%)	7/866 (0.8%)	2.27E-24	9.08E-24
Physical therapy	1167/1577 (74.0%)	106/935 (11.3%)	1.01E-16	2.69E-16
Speech therapy	45/1577 (2.9%)	3/935 (0.3%)	1.08E-6	1.92E - 06
Other/occupational therapy	225/1577 (14.3%)	22/935 (2.4%)	4.52E-26	2.41E-25

Continuous variables are given as mean (Q1-Q3), binary variables are given as absolute numbers and percentage.

Tests: exact test by Fisher for binary variables and Mann–Whitney U-test for continuous variables, two-sided p values; adjusted p values are p values adjusted for multiple testing using the procedure by Simes [7].

Difference in gestational age and birth weight not tested because different by definition, difference in age not tested because not of major interest.

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