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ORIGINAL ARTICLE

# Analysis of compliance, morbidities and outcome in neurodevelopmental follow-up visits in urban African-American infants at environmental risk

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The objectives of this study were to determine compliance rate in a uniform, urban African-American patient population at environmental risk for adverse neurodevelopmental outcome and to define risk factors for non-compliance with neurodevelopmental follow-up. A retrospective chart review was performed which included 481 infants with birth weight (BW) of 495–4195 g and gestational ages (GAs) between 23 and 42 weeks born at our hospital. Statistical analysis was performed using the Jonckheere–Terpstra test for ordinal variables. For $2 \times 2$ tables, $\chi^2$ test and Fisher's exact test ($P < 0.05$) were used. To determine significant predictive variables, data were analyzed by multiple logistic regression with one independent variable at a time. Infants compliant with follow-up had significantly more morbidities in the very low BW category (≤1500 g) than infants with larger BW. The highest compliance rate (70%) was found among the smallest and most immature (GA ≤28 weeks) infants. Based on this finding, we postulate that the number of infants with severe disability is not likely to be underestimated. The significantly more frequent developmental anomalies found in the largest BW (≤2500 g) category raises significant concern, though findings in this subset of infants may not be representative of the whole population. There was no significant difference between the compliant and non-compliant groups regarding socio-economic status. Severe or multiple morbidities and prolonged hospital stay may provide parents with greater opportunity to learn and understand about the infant's condition which may lead to greater compliance.

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## Introduction

With the improving survival rate of very low birth weight (VLBW; <1500 g birth weight (BW)) and extremely low birth weight (ELBW; <1000 g BW) infants, the number of infants with high risk to have adverse neurodevelopmental outcome is increasing.[1,2] Most of the follow-up studies focus on the outcome of these VLBW/ELBW patients.[3,4] More recently, several reports have been published concerning morbidity and outcome of the so-called 'large preterm' babies.[5,6] This group, along with term infants, accounts for two-thirds of the patients with severe impairment, such as cerebral palsy (CP), hence the significance of outcome studies in these larger and more mature infants.[7,8]

There are as many as 50% of infants following discharge from the Neonatal Intensive Care Unit (NICU) who are non-compliant with neurodevelopmental follow-up. Most of the centers aim at achieving at least 80% compliance rate.[9] Multiple factors may be involved for loss to follow-up including low socio-economic status, young maternal age, low maternal educational level, ethnicity/minority status, history of missed appointments and communication problems.[10–12]

The percentage of infants lost to follow-up visits may influence the number of reported adverse outcomes, especially in ELBW infants leading to over- or underestimation of infants with disabilities.[13–15] Castro *et al*. developed a model to predict outcomes of infants being lost to follow-up and to examine the possibility of a bias in reported outcomes in ELBW infants.[14] They found that the number of infants with disabilities is likely to be overestimated.

The purposes of this study were to (1) determine the compliance rate of VLBW infants, those with BW between 1501 and 2499 g (including 'large preterm' infants), and those with BW ≥2500 g; (2) compare morbidities and socio-economic factors in those who have been compliant with those infants who have been non-compliant with follow-up; and (3) identify risk factors that may influence non-compliance. Based on the fact that many of our patients belong to a socio-economically disadvantaged population at environmental risk, we hypothesized that (1) some infants with adverse outcome may have been lost due to non-compliance, thus the rate of adverse outcome may have been underestimated and (2) infants with more severe in-hospital course in this cohort would be more significantly compliant than those with less severe morbidities.

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## Method

The Institutional Review Board approved this study, which was a retrospective analysis performed on a cohort of 481 infants with BW of 495–4195 g and gestational age (GA) between 23 and 42 weeks discharged from a level III NICU between July 2002 and June 2007. The compliant group consisted of 264 infants (55%), while 217 infants (45%) were non-compliant with neurodevelopmental follow-up. Compliance was defined as participation and complete evaluation in the neurodevelopmental follow-up clinic on at least one occasion following discharge from the hospital. Adverse neurodevelopmental outcome was defined as delay in one or more domains of development (i.e. gross and fine motor, speech and language, cognition and problem-solving skills), diagnosis of CP or sensory deficits (i.e. visual and hearing impairment). The first visit to the neurodevelopmental follow-up clinic was scheduled at 4 months corrected age for degree of prematurity.

Clinical variables were collected by retrospective chart reviews. Infants discharged from or referred by other institutions and infants other than African-American by race were excluded from the study. The study groups represented infants of a uniform, urban African-American, underserved patient population at environmental risk. Inclusion criteria for the study, as well as referral criteria for follow-up, consisted of those with $\leqslant$1500 g BW, GA of $\leqslant$32 weeks, larger or more mature infants with a complicated in-hospital course (i.e. multiple or major surgeries or major congenital anomalies of any organ system), and those with abnormal clinical neurological signs.

Clinical variables for both compliant and non-compliant infants included BW, GA, gender, small for gestational age (SGA), mode of delivery (cesarean section *v.* vaginal delivery), multiple pregnancy, need for resuscitation defined as need for positive pressure ventilation at birth, respiratory distress syndrome (RDS) with surfactant replacement, prolonged mechanical ventilation (PMV) defined as mechanical ventilation >7 days of duration, bronchopulmonary dysplasia (BPD) defined as need of additional $O_2$ at 36 weeks corrected age, patent ductus arteriosus (PDA), sepsis confirmed by bacterial culture, retinopathy of prematurity (ROP) diagnosed by pediatric ophthalmologist, necrotizing enterocolitis (NEC), and abnormal central nervous system (CNS) imaging study results including intraventricular hemorrhage (IVH), periventricular leukomalacia, CNS developmental anomalies, ventriculomegaly, parenchymal infarct and hypoxic ischemic encephalopathy. Other diagnoses or reasons for NICU admission included BW < 2250 g, GA < 35 weeks, observation for infection, respiratory problems other than RDS, infants of diabetic mothers and hyperbilirubinemia. These variables are consistent with NICU admission criteria established in our institution, however, since they represent mild morbidities and generally do not increase risk for adverse outcome, some of them are not included in Table 4.

Follow-up appointments were arranged for each infant prior to discharge from the NICU and provided to the parents in writing. Each infant's family received a written reminder regarding the appointment 1 week prior to the actual follow-up visit by mail. This was reinforced by a telephone-call reminder 1–2 days prior to the visit. If the infant did not come to the follow-up clinic, another letter was sent in each case to remind the family of the missed visit, including information for rescheduling.

Follow-up neurodevelopmental evaluation consisted of history, physical examination and anthropometric measurements. Measures of neurodevelopmental outcomes included standard neurologic examination and the DDST (Denver II Developmental Screening Test).[16] Cognitive/visual fine motor and speech and language evaluation were made using the CAT/CLAMS (Cognitive Adaptive Test/Clinical Linguistic and Auditory Milestone Scale).[17] Infants were followed until 3.5 years of age. Developmental quotients were calculated for both corrected and non-corrected ages. Hearing tests were performed in each case by otoacoustic emission and confirmed by audiometry if necessary. Ophthalmology follow-up was arranged before discharge from the hospital if indicated, with the need for further follow-up determined by a pediatric ophthalmologist.

Data were analyzed with the use of SAS for Windows (version 9.2). For ordinal variables, we used the Jonckheere–Terpstra test. For $2 \times 2$ tables, we used the $\chi^2$ test and Fisher's Exact Test ($P < 0.05$).[18] To determine significant predictive variables, data were analyzed by multiple logistic regression with one independent variable at a time.

## Results

Maternal age at the time of birth varied from 13 to 45 years of age. Marital status consisted of 84–91% single-parent families. There was no difference between the compliant and non-compliant groups with regard to maternal age.

Table 1 includes the total number of live births at our hospital during the data collection period, including all African-American infants, those who survived, referred for neurodevelopmental follow-up, and those who returned to the follow-up clinic.

Table 2 shows patient data categorized by BW in the compliant/non-compliant groups. Controlling for GA, we found that there was no significant difference between the two groups across all BW categories ($P = 0.3$). Higher BW was associated with lower likelihood for being compliant. Without controlling for GA, higher BW was significantly associated with lower compliance ($P < 0.001$; OR: 1.49; 95% CI: 1.2–1.86).

Table 3 includes compliance by GA. The most compliant subset of infants had GA $\leqslant$ 28 weeks. Lower GA was associated with higher likelihood for compliance, with a difference between compliant and non-compliant groups that was close to significance ($P = 0.06$; OR: 1.21; 95% CI: 0.99–1.47).

Table 4 shows clinical variables of compliant and non-compliant patients with respect to BW. PMV, BPD, ROP and

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**Table 1.** *Total number of infants (n = 8149) born at medical center during study period by birth weight*

| Birth weight (g) | ⩽1500 | 1501–2499 | ⩾2500 |
|---|---|---|---|
| Infants born at hospital during data collection period (*n*) | 250 | 706 | 7193 |
| All NICU admissions | 250 | 583 | 2278 |
| All African-American NICU admissions | 236 | 553 | 2165 |
| African-American (*n*) | 236 | 666 | 6748 |
| African-American infants who survived (*n*) | 179 | 656[a] | 6741[b] |
| Referred for follow-up (*n*) | 179 (100%) | 188 (29%) | 114 (1.7%) |
| Infants who returned to clinic (*n*) | 125 | 80 | 59 |

NICU, Neonatal Intensive Care Unit.
[a] African-American infants admitted to well baby nursery (1501–2499 g birth weight) = 113 infants.
[b] African-American infants admitted to well baby nursery (⩾2500 g birth weight) = 4583 infants.

**Table 2.** *Patient compliance by birth weight*

| Birth weight | Follow-up (*n*) | No follow-up (*n*) |
|---|---|---|
| ⩽1500 g (*n* = 179) | 125 (70%) | 54 (30%) |
| 1501–2499 g (*n* = 188) | 80 (43%) | 108 (57%) |
| ⩾2500 g (*n* = 114) | 59 (51%) | 55 (49%) |
| Total (*n* = 481) | 264 (55%) | 217 (45%) |

**Table 3.** *Patient compliance by gestational age*

| Gestational age | Follow-up visit (*n*) | No follow-up visit (*n*) |
|---|---|---|
| ⩽28 weeks (*n* = 111) | 82 (68%) | 29 (32%) |
| 29–32 weeks (*n* = 129) | 76 (59%) | 53 (31%) |
| 33–37 weeks (*n* = 126) | 54 (43%) | 72 (57%) |
| ⩾37 weeks (*n* = 115) | 52 (45%) | 63 (55%) |
| Total (*n* = 481) | 264 (55%) | 217 (45%) |

NEC were found almost exclusively in the ⩽1500 g BW category. Significantly, more infants needed PMV ($P = 0.006$), had BPD ($P = 0.001$) and developed ROP ($P = 0.05$) in the compliant group. More infants needed resuscitation among the compliant patients; it reached significance among the VLBW infants ($P = 0.05$) and in the largest BW category ($P = 0.001$).

Major developmental anomalies were diagnosed in the two larger BW categories. All infants with congenital anomalies (other than CNS) or genetic syndromes were non-compliant in the 1501–2499 g BW category. Among the largest infants, significantly more infants with congenital anomalies (other than CNS) or genetic syndromes were found in the non-compliant as compared with the compliant group ($P = 0.0005$).

Among the VLBW infants, two had CNS developmental anomalies, with both being non-compliant with follow-up. In the largest BW category, eight infants (13.5%) with CNS developmental anomalies were compliant while eight were non-compliant (14.5%).

There was no significant difference between infants with follow-up and no follow-up with regard to gender, mode of delivery, SGA, multiple gestations, RDS with surfactant replacement, sepsis, NEC and abnormal CNS findings in imaging studies.

After adjusting for BW and GA in the VLBW infants, the need for PMV ($P = 0.03$; OR: 2.70; 95% CI: 1.08–6.75) and presence of BPD ($P = 0.008$; OR: 3.55; 95% CI: 1.39–9.03) were still significant morbidities in the compliant group of infants. In the 1501–2499 g BW category, with the same adjustment for BW and GA, abnormal CNS imaging results were found in significantly more infants in the compliant group ($P = 0.05$; OR: 3.99; 95% CI: 0.95–16.76). Among the largest infants, significantly more infants needed resuscitation in the compliant group ($P = 0.0009$; OR: 3.99; 95% CI: 1.77–9.01).

Within the subgroup of infants with adverse outcome, 32 infants were diagnosed with CP, which was defined as a group of non-progressive, but often changing motor impairment syndromes secondary to lesions or abnormalities of the brain arising at any time during brain development.[19] This CP rate was found in 18/125 VLBW infants (99/1000 survivors; 75/1000 live births). Among 1501–2499 g BW category, the CP occurrence was 4/80 (6.1/1000 survivors; 6/1000 live births), while CP was represented in the largest BW category (⩽2500 g) with 10/59 infants (1.45/1000 survivors; 1.46/1000 live births). Most initial visits to the neurodevelopmental clinic occurred when the infants were four months of age, with age correction, if required. They were then asked to return to clinic for subsequent follow-up visits at 4- to 6-month intervals until 3 years of age. The rate of occurrence for CP in the two larger BW categories may be underestimated, as only 37.5% of the infants in the 1501–2499 g BW group returned again to clinic after 12 months of age, and 25% of the largest BW group were seen in clinic following 12 months of age. The compliance rate in the smallest BW group in infants older than 12 months of age was much greater (72%), thus resulting in a better estimate of the rate of occurrence of CP.

Table 5 includes insurance data in both compliant and non-compliant groups. There was no significant difference

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**Table 4.** *Clinical variables and patient compliance by birth weight*

| Variables | Birth weight | | | | | | | | |
|---|---|---|---|---|---|---|---|---|---|
| | ⩽1500 g ($n = 125$) | | | 1500–2499 g ($n = 80$) | | | ⩾2500 g ($n = 59$) | | |
| Follow-up visit | Yes ($n = 125$) | No ($n = 54$) | Statistical significance | Yes ($n = 80$) | No ($n = 108$) | Statistical significance | Yes ($n = 59$) | No ($n = 55$) | Statistical significance |
| Males | 66 | 27 | ns | 36 | 84 | ns | 37 | 22 | ns |
| Multiple pregnancy | 17 | 13 | ns | 16 | 12 | ns | 3 | 4 | ns |
| Cesarean section | 95 | 42 | ns | 52 | 73 | ns | 36 | 62 | ns |
| SGA | 14 | 12 | ns | 3 | 25 | ns | 1 | 0 | ns |
| Resuscitation | 91 | 31 | 0.05 | 20 | 32 | ns | 36 | 16 | ns |
| RDS/surfactant | 90 | 33 | ns | 6 | 10 | ns | 0 | 0 | ns |
| PMV | 50 | 14 | 0.006 | 0 | 1 | ns | 0 | 0 | ns |
| BPD | 55 | 10 | 0.001 | 0 | 0 | ns | 0 | 0 | ns |
| PDA | 64 | 21 | ns | 3 | 7 | ns | 0 | 0 | ns |
| ROP | 46 | 13 | 0.05 | 0 | 0 | ns | 0 | 0 | ns |
| NEC | 17 | 7 | ns | 0 | 0 | ns | 0 | 0 | ns |
| Genetic syndromes, developmental anomalies other than CNS | 0 | 0 | ns | 0 | 18 | ns | 7 | 23 | 0.0005 |
| PNI | 81 | 33 | ns | 6 | 4 | ns | 4 | 1 | ns |
| Abnormal CNS Imaging study | 30 | 9 | ns | 7 | 3 | ns | 19 | 11 | ns |
| CNS developmental anomalies | 0 | 2 | ns | 2 | 0 | ns | 8 | 8 | ns |

SGA, small for gestational age; RDS, respiratory distress syndrome; PMV, prolonged mechanical ventilation; BPD, bronchopulmonary dysplasia; PDA, patent ductus arteriosus; ROP, retinopathy of prematurity; NEC, necrotizing enterocolitis; CNS, central nervous system; PNI, post natal infection.

**Table 5.** *Insurance data of compliant and non-compliant infants*

| | Compliant with follow-up ($n = 264$) | Non-compliant with follow-up ($n = 217$) |
|---|---|---|
| No insurance (*n*) | 66 (25%) | 42 (19%) |
| Medicaid/managed care (*n*) | 172 (65%) | 149 (69%) |
| Other (*n*) | 26 (10%) | 26 (12%) |

**Table 6.** *Telephone survey of reasons found for non-compliance*

| Reason for non-compliance | *n* |
|---|---|
| No phone (disconnected service, no answer) | 128 (59%) |
| Had follow-up in other clinics: | |
| Doing well | 19 (9%) |
| Receives services[a] | 11 (5%) |
| Services no longer needed due to doing well | 18 (8%) |
| Rescheduled appointment after phone calls | 16 (7%) |
| No need for follow-up/refused to attend | 17 (8%) |
| Moved | 4 (2%) |
| Chronic care facility | 2 (1%) |
| Died | 2 (1%) |

[a] Services included physical therapy, occupational therapy, speech-language/oral-motor therapy and/or special instruction.

between the two groups regarding insurance status or lack of medical insurance ($P = 0.3$).

Table 6 indicates reasons that were obtained from parents or relatives through a telephone survey for failure to attend follow-up visits. The phone calls were conducted by staff members of the follow-up clinic. The most common finding was inaccessible families due to phones not in service/disconnected or no answers after repeated phone calls. Thirty of the infants had follow-up care in another facility, with 19 of them doing well and 11 receiving services according to the information from the families. Seventeen of the families indicated that they found it unnecessary to attend follow-up. At the conclusion of the study, 18 infants were discharged from all therapies and were doing well, which prompted the parents to believe that there was no further need for neurodevelopmental follow-up. Following phone calls due to non-compliance, 16 infants were rescheduled for follow-up in our clinic. In this group, two had a diagnosis of CP, while the remainder showed variable degrees of adverse outcome in one or several domains of neurodevelopment.

## Discussion

Perinatal morbidities may predict neurodevelopmental outcome. The identified neonatal morbidities indicating risk for adverse outcome in this study are in agreement with previously published data among VLBW infants[14,15] as well as in infants who belonged to the two larger BW categories.[5–7]

Compliance with neurodevelopmental follow-up was related to complicated perinatal course among the VLBW infants. In the compliant group, significantly more infants had severe, often multiple morbidities, including need for resuscitation, PMV, BPD and ROP. Since infants with less morbidity and less complicated course were non-compliant, we speculate that underestimation of the number of infants with severe adverse outcome is not likely in this BW category.

In our standard of care, VLBW infants were routinely referred for neurodevelopmental follow-up. The larger infants who were included in this study consist of a selected subset of infants with congenital anomalies or other CNS morbidities, which may not be representative of the population studied. Among the infants in the two larger BW groups, significantly more infants with congenital anomalies were found in the non-compliant group.

Communication problems[20] between families and health-care providers may reduce the understanding of the importance of the follow-up visit and may contribute to non-compliance. Other factors that may be associated with non-compliance include low socio-economic status, single parent family and history of multiple rescheduled appointments.[21,22]

The main findings of this study show a disadvantaged patient population with low socio-economic status reflected by race, having mainly single parent families and low income shown by their insurance status. Therefore, our patients fit the description and definition of a population at environmental risk which 'include those children whose caregiving circumstances and current family situation place them at greater risk for delay than the general population'.[23]

Good compliance in neurodevelopmental follow-up is crucial for identifying infants with impaired development and for initiating therapy in a timely fashion to ensure improved outcome. Furthermore, outcome data collection and analysis of compliance may change the organization and goals of follow-up and provide valuable information about the actual patient population. Follow-up at a later age may make it possible to diagnose severe outcome such as CP with more accuracy, however the older the child, the less likely the parents are to return for neurodevelopmental follow-up.[11,24]

Non-compliance may lead to suboptimal patient care and is not cost-effective for health-care providers.[11,25–27] Compliance rate in this study is less than the desired rate of 80% and above.[9] However, the highest compliance rate was found among infants with the smallest BW (VLBW) and lowest GA, which represent the subgroup of patients with highest risk for

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adverse outcome. The number of infants diagnosed with developmental anomalies or genetic syndromes found in the non-compliant group raise serious concerns.

In summary, in the smallest infants, there were significantly less morbidities found in the non-compliant group. In agreement with several previous reports,[14,23] it is likely that the number of VLBW infants with severe disabilities including CP is not underestimated due to non-compliance. Conversely, because a number of infants with serious morbidity among the two larger BW categories were non-compliant, adverse outcome of these patients is likely to be underestimated. Since the compliant families did not differ from the non-compliant ones with regard to race, maternal age, marital and insurance status as measures of socio-economic status, we conclude that the greater compliance of the families of VLBW infants may be explained by other factors. Owing to the more severe, frequently multiple morbidities and prolonged hospital stay in these infants, the parents may have had greater opportunity to learn and understand about the infant's condition and the necessity and importance of neuro-developmental follow-up. Furthermore, although we have incomplete data regarding maternal educational level, we assume that low level of education[11] may contribute to non-compliance in our patients' families. Although we do not have complete data, we speculate that, in certain cases, language barrier may have contributed to non-compliance.

The strengths of this study include the uniform, African-American population whose morbidity and mortality data are well published, but outcome data are less studied.[28,29] Few data are available regarding compliance in general.[11,20–22] Unlike most follow-up studies, this analysis does not focus on the VLBW infants alone, but also includes information regarding morbidity and compliance in all BW categories, including large preterm and term infants. The limitations of the study are its retrospective nature, the relatively small number of infants in certain categories, that is, the number of infants with abnormal CNS study results or developmental anomalies in the respective BW groups.

To improve future compliance, we aim to practice more advanced implementation of the NIDCAP (Newborn Individual Developmental Care Assessment Program) in our NICU[30] in order to improve parent education, understanding of the infant's status and communication among families and health-care providers. We are making further efforts to identify infants at risk for adverse outcome at an early age by including Prechtl's method of general movement assessment[31] in the NICU as well as in our follow-up clinic.

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## Statement of Interest

None.

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