

# Improving health care usage in a very low birth weight population

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**Background:** Prematurity is the biggest contributor to admissions in the neonatal intensive care unit (NICU). The period following hospital discharge is a vital continuum for the very low birth weight (VLBW) infant. The objective of this study was to assess the impact of a unique discharge and follow-up process on the outcomes of VLBW infants leaving the NICU.

**Methods:** All outpatient health care usage by VLBW infants born in the study year (cases) was retrospectively tracked through 12 months of age. A cohort of healthy newborn infants were matched by birthdate to each VLBW infant (controls) and similarly tracked.

**Results:** In this study, there were 85 cases and 85 controls. The mean gestational age at birth for the cases was 29.1±2.7 weeks with a mean birth weight of 1079±263 g. That of the controls was 38.9±1.3 weeks and 3202±447 g. Over 90% of both populations had Medicaid coverage. All VLBW infants received care at the Special Care Developmental Follow-Up Clinic. When compared with the controls, VLBW infants discharged from the NICU made fewer acute, unscheduled visits to the Emergency Department or Urgent Care Clinic (2.3±2.5 vs. 3.7±3.5;  $P=0.007$ ) despite their high-risk medical and social status. Their growth pattern showed significant "catch-up" and was similar to the matched controls at the last scheduled visit for each group.

**Conclusions:** Outcomes including health care utilization in high-risk infants can be improved through meticulous discharge planning and follow-up measures that utilize existing hospital infrastructure to provide affordable comprehensive care.

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## Introduction

Prematurity continues to be the biggest world-wide contributor to neonatal morbidity and admission to the neonatal intensive care unit (NICU).<sup>[1-4]</sup> In 2008, over 47 000 very low birth weight (VLBW) infants were born weighing 1500 g or less in the United States alone.<sup>[1]</sup> The NICU discharge is a momentous occasion for the family. Given the amount of resources expended on these babies, the health care system should view the period after hospital discharge as a vital continuum of care for the VLBW infants.<sup>[5]</sup>

The link between prematurity and a higher rate of acute care visits has been established.<sup>[2,6]</sup> Several studies have been conducted in the US and abroad looking specifically at VLBW infants and their medical needs following hospital discharge.<sup>[6,7]</sup> While there is no question that significant gains have been made with regard to survival of these infants, their increased morbidity and health care costs beyond discharge remain significantly higher than those of healthy term infants.<sup>[6,8]</sup> On average, the former VLBW infant will cost \$1400 in acute care physician visits compared with \$1142 for late preterm infants and \$717 for term infants<sup>[6]</sup> (calculated in 1987 dollars and based on limited studies on the subject). After initial discharge, VLBW infants will use on average over \$93 800 (1987 dollars) in treatments.<sup>[6,8]</sup> The late preterm infant will accrue costs of \$12 247 in the first year of life and the term infant less than a third of this cost.<sup>[9]</sup>

The American Academy of Pediatrics (AAP) Committee for Fetus and Newborn recommends that VLBW infants, once discharged from the NICU, have access to health care providers experienced in the follow-up care of high-risk infants, and to an organized program that allows for tracking and surveillance of weight and developmental milestones (Committee for Fetus and Newborn, 2008).<sup>[10,11]</sup>

In this retrospective study, a comprehensive follow-

up strategy was assessed to determine its impact on the outcomes including pattern of health care delivery in a vulnerable population of VLBW infants. The primary objective of the study was to examine the effectiveness of our Special Care Developmental Follow-Up Clinic (SCC) in improving healthcare usage in VLBW infants discharged from the NICU in the first year of life. As secondary objectives, we looked at growth and referral to state funded early intervention (EI) programs as outcome measures.

## Methods

This study was conducted as a retrospective case-control study following institutional review board approval. The study unit is a 49-bed Level III NICU. More than 100 VLBW infants are routinely admitted each year. Upon discharge, all of these infants are eligible for follow-up care in the SCC.

### Enrollment

All VLBW infants with less than 32 weeks of gestation, born between January 1 and December 31, 2008 (cases), were tracked and followed up through 12 months of age. Controls were selected using the institutional birth logs, with the first documented healthy infant born at greater than 36 weeks of gestational age, on the same date as the identified VLBW infant, and never requiring NICU care, being selected for each VLBW infant included in the study, and tracked for the same time period. Infants that did not receive their primary care at the institution through the first year of life were excluded because health care visits could not otherwise be reliably tracked.

### Discharge planning and the SCC

All VLBW infants were subjected to the standard discharge process. A comprehensive discharge plan was devised for each infant just prior to discharge through a weekly planning meeting held in the NICU, and attended by the clinical team managing the SCC. At this meeting, the NICU medical personnel were charged with coordinating healthcare needs for each infant leaving the NICU, including prescription management and referrals for subspecialty care. Each infant was provided with a personal physician, either a neonatologist or a neonatal fellow, responsible for follow-up care in the SCC starting after discharge. A discharge summary was made available to the staff in the SCC, and to the infant's primary care provider, detailing the NICU stay and communicating ongoing problems that required long-term management.

The SCC was designed as a multi-disciplinary

clinic that served many of the outpatient needs of the high-risk NICU "graduates". The SCC was staffed by a team of neonatologists, a neonatal nutritionist, physical and occupational therapists, a social worker, Licensed Practical Nurse clinic coordinator, and a home apnea monitor technician. The clinic coordinator was charged with scheduling the visits, and with ensuring clinical plan compliance through follow-up reminders via telephone calls, letters and appropriate triaging of sick calls. By this role, she maintained a working relationship with the patients' families.

For the majority of the infants discharged from the NICU, the SCC also represented an additional source of care by complementing that given by the primary care physician. Each member of the SCC team acted as an educator for the families, and time was spent on anticipatory guidance through advisory calls and during clinic visits, both prior to discharge and once the infant went home. This multi-disciplinary approach allowed the team to be aware of, and to deal with, a broad range of medical and social issues affecting the patients and their families.

The SCC also served as a liaison with the patient's primary care provider and other subspecialists (such as ophthalmologist, audiologist, surgeon, pulmonologist, neurologist and cardiologist) as needed. All VLBW infants also received routine primary medical doctor visits.

### Discharge planning for controls

The controls were discharged from the normal newborn nursery by the nurse practitioner, pediatric resident and/or primary medical doctor charged with their hospital care after a standard 2-4 day stay. Each of the cases and controls was assigned a primary medical doctor by standard means (parent/insurance carrier preference or default) prior to discharge.

### Follow-up care

The VLBW infants were seen every 2-3 months during the first year of life. They were seen monthly while receiving oxygen and/or cardiorespiratory monitoring, or if they had other significant issues such as poor feeding/weight gain. Well-child care follow-up for both VLBW infants and healthy controls were scheduled based on the Recommendations for Preventive Pediatric Health Care (AAP Committee on Practice and Ambulatory Medicine Pediatrics, 2000 revised in 2007).<sup>[12]</sup>

Medical care for both groups was provided through a network of pediatric and family practice-based clinics, both on campus and in the community, staffed by primary care physicians, nurse practitioners,

registered nurses and social workers. Services included preventative, acute and urgent care, triaging of sick calls and follow-up. In addition, the emergency department provided 24-hour acute care coverage including staffing of an urgent care section devoted to the care of pediatric patients. All infants had equal access to these services. As the hospital serves a highly indigent and vulnerable socio-economic risk population, social service interventions were provided equally to both groups.

### Coding for severity of diagnoses at acute visits

A coding system for the severity of illness triggering each acute care visit was developed using the provided ICD-9 code. Based on the intervention required, each presenting illness was classified as follows: benign illness, such as diaper rash or rhinorrhea, requiring only anticipatory guidance or over-the-counter medications was scored as 1; more severe illness such as ear infections, fever of unknown source, vomiting with dehydration requiring a prescription medication, additional evaluation or follow-up by a provider was scored as 2, and more serious conditions such as bronchiolitis or pneumonia requiring specialized in-clinic treatment or follow-up care and/or hospitalization was scored as 3. Only one score was assigned per visit. Where more than one condition triggered the acute visit, the more severe condition was used for coding.

### Socio-economic status (SES) and growth

The availability of health insurance coverage and the type of health insurance were used as an indicator of SES. Growth data for each of the participants at last visit were collected. When weight percentiles were used at corrected age as a surrogate for well-being, all growth parameters were adjusted to a gestation age of 40 weeks to account for prematurity and plotted on the World Health Organization growth curve.

### Data collection

Data were collected using hospital's electronic medical record that allowed review of all institutional encounters. This included all physicians and other allied health professionals, thus obtaining detailed tracking of health care utilization for all study participants. Data were also collected for basic demographic details such as gestational age at birth, birth weight and gender, length of initial hospital stay, number of discharge diagnoses requiring follow-up or treatment after discharge, health insurance coverage, number of scheduled visits to primary care provider and specialty clinics, number of emergency room and urgent care visits and severity of diagnoses, EI referral and growth data for each visit.

### Statistical analysis

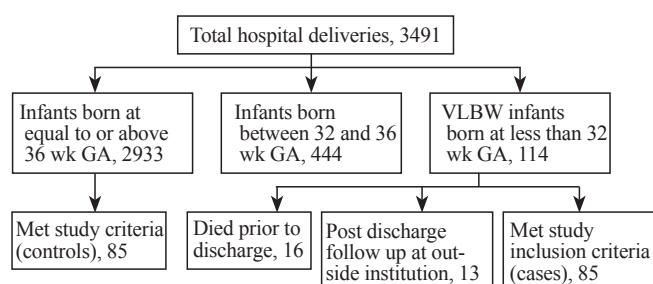
All analyses were conducted using SPSS® software. We computed descriptive information on patient access of the health care system [including emergency department (ED), well-child care, subspecialty care, and allied health care visits] using information abstracted from the Electronic Medical Record. All means were reported within 1 standard deviation. All *P* values less than 0.05 were reported as statistically significant.

## Results

In 2008, there were 3491 institutional births, of which 120 (3.4%) were VLBW infants born at less than 32 weeks completed gestational age. Sixteen of these infants died prior to hospital discharge and were therefore excluded from the study (Fig.).

The majority of VLBW infants received care in our hospital network for the first year of life (85/98; 87%) and therefore met the inclusion criteria (cases). These were matched to 85 controls. The mean gestational ages, birth weights and length of stay of the cases and controls were statistically different as summarized in Table 1.

While the controls were predominantly healthy at discharge, the cases had an average of 3 active diagnoses at discharge that required follow-up and/or treatment once the infant went home (3±1.5 vs. 0.7±0.3;



**Fig.** Algorithm showing study enrollment. GA: gestational age; VLBW: very low birth weight.

**Table 1.** Demographic characteristics of study participants

Variables	Cases ( <i>n</i> =85) (mean±SD)	Controls ( <i>n</i> =85) (mean±SD)	<i>P</i> value
Mean gestation age at birth (wk)	29.1±2.7	38.9±1.3	<0.001
Mean birth weight (kg)	1.079±0.263	3.202±0.447	<0.001
Male gender	48/85 (56%)	45/85 (53%)	0.347
Medicaid (%)	77/85 (91%)	78/85 (92%)	0.578
Median length of hospital stay (d)	70.6±52.0	2.3±1.6	<0.001
Number of active diagnoses at discharge	3.2±1.5	0.3±0.7	<0.001

SD: standard deviation.

**Table 2.** Summary description of comparison of attendance of scheduled health care visits made by all very low birth weight infants and their controls

Variables	Cases (mean±SD)	Controls (mean±SD)	P value
Total mean number of well child care visits attended	2.9±1.9	4.4±1.0	<0.001
Total mean number of Special Care Clinic attended	5.6±2.1	0.0±0.0	<0.001
Total mean number of Subspecialty Clinics attended	17.8±1.6	5.5±3.4	<0.001
Early intervention referrals	76/85 (89%)	7/85 (8%)	<0.001
Median age at last visit, first year of life (mon)	9.6±2.9	9.1±2.3	0.098
Median corrected age at last visit	7.0±2.0	8.8±2.3	<0.001
Mean weight at last visit (kg)	7.3±1.5	8.8±1.5	0.674

SD: standard deviation.

**Table 3.** Summary description of a comparison of the acute health care usage by all very low birth weight infants and their controls and severity of diagnosis during these visits

Variables	Cases (mean±SD)	Controls (mean±SD)	P value
Mean urgent care visits	1.7±1.9	2.9±2.8	0.004
Mean emergency department visits	0.7±1.3	0.8±1.4	0.611
Mean total sick visits	2.3±2.5	3.7±3.5	0.007
Severity of diagnosis	1.1±0.9	1.3±0.8	0.904

SD: standard deviation.

$P<0.001$ ). Medicaid coverage was similar in both cases and controls [78/85 (92%) vs. 77/85 (91%);  $P=0.578$ ].

The summary of scheduled visits made by each group in the first year of life is shown in Table 2. More eligible VLBW infants benefited from EI referrals through Help Me Grow (Ohio state-funded program for expectant mothers and their children that provides health and developmental interventions to eligible children) than did the controls [76/85 (89%) vs. 7/85 (8%);  $P<0.001$ ] and received more social work visits (2±1.6 vs. 0.4±0.7,  $P<0.001$ ). When the mean weight for corrected age at last scheduled visit was compared, with the last scheduled visit being at 7 months corrected age for cases and 8.8 months for controls, there was no significant weight difference between the two groups (7.3±1.5 kg vs. 8.8±1.5 kg;  $P=0.674$ ).

The VLBW infants discharged from the NICU made fewer unscheduled visits to the Urgent Care Clinic, and fewer total number of acute type or unscheduled visits in total. The number of ED visits was similar. Based on our severity of the illness scoring system, there was no difference in the severity of illness between cases and controls at presentation (Table 3).

## Discussion

In our study, VLBW infants were compared with term infants in the same community to control outcome differences that could be directly related to socio-demographic or economic factors. There is a clear need for a unique approach in planning long-term care in a medically fragile population. This has been addressed in several studies and reviews looking at the subject. Cohen et al<sup>[13]</sup> looked at healthcare models targeted at children with medical complexity (CMC). In their review, they proposed the need for family-identified initiatives, and described the medical usage patterns of CMC as being unique from other children, with projected increases in the frequency of hospital visits and admissions, as was the case in scheduled outpatient visits in our VLBW population. They concluded that care-coordination is successful in decreasing haphazard medical usage in CMC. Traditional methods of delivering healthcare cannot meet the needs of fragile children or their families. In our model, a customized health care delivery system reduced unplanned hospital visits in an otherwise high-risk population to less than those experienced by healthy infant controls.

Another important goal in providing follow-up for all children is to provide quality comprehensive medical care in a single context. This aligns with the ongoing national prerogative that all children have a medical home (Healthy People 2010).<sup>[14]</sup> By involving the neonatal team in the provision of regular follow-up care, and by maintaining a key role in continual parent education, the SCC met the AAP definition of a medical home. By AAP definition, comprehensive medical care is provided by a team that ensures all the needs of the patient are met, including access and coordination of specialty care, education and support, and connection with community services that improve the overall health of the patient.<sup>[15]</sup> Raphael et al<sup>[16]</sup> in their analysis of the impact of a medical home on children with special needs reported an associated reduction in health care disparities when these children had access to a definite medical home. In their study, having a medical home reduced the odds of emergency care utilization to 0.81 in susceptible children. In our study, we observed a reduction to 0.66, in the odds of emergency care utilization, when VLBW infants were compared with healthy infant controls. Gray et al<sup>[8]</sup> in their cohort of very premature infants, followed up to two years of age, observed that in the absence of any intervention, there was a definite trend towards increased outpatient visits in VLBW infants. In their study, frequent hospital visits and admission were linked to low birth weight, and to an increased number of people living in the household, a marker for socioeconomic status. Given our similar patient population, we deduced that providing a medical

home for VLBW infants altered unplanned healthcare usage in favor of preventive and subspecialty care services.

Medicaid health coverage has been used by government agencies as a correlate to social class.<sup>[17]</sup> This is based on data for Medicaid eligibility criteria as determined by the United States government that ties family income and relationship to the poverty level. Possession of Medicaid insurance is a proxy for low SES.<sup>[18]</sup> Over 90% of our study population was under Medicaid health care coverage. In a cohort of 3-year-old former VLBW infants, Brookes-Gunn et al<sup>[19]</sup> demonstrated that children of parents with low SES would have more emergency department visits than those with a higher SES, resulting in fragmented care and poor physician relationships, potentially further compromising their health status. Olson et al<sup>[20]</sup> in a study evaluating health outcomes as relates to family income and disparities in infants and neonates in the United States between 2000 and 2004, concluded that the poorest children inevitably would have the worst health outcomes. In contrast, we demonstrated that ready access to comprehensive healthcare in largely impoverished communities may help to ensure better outcomes, such as growth, by encouraging the use of consistent, scheduled specialty clinics and allied support to provide backbone medical care to chronically ill infants.

Infants on Medicaid are also more likely to have risk factors relating to adverse cognitive outcomes. It can be postulated that these infants will benefit from state-funded EI programs, regardless of a history of prematurity.<sup>[21,22]</sup> EI service referrals for infants attending the SCC (89%) were far higher than those quoted in similar studies, such as Gray et al (40%).<sup>[8]</sup> We hypothesize that this is a direct result of a more robust referral and follow-up system provided in the SCC. Orton et al<sup>[23]</sup> have shown that EI programs for preterm infants have a positive influence on cognitive outcomes in the short to medium term. Campbell et al<sup>[21]</sup> reported positive effects of EI on intellectual and academic achievement in children from poor families in the Carolina Abecedarian Project.

Children in poor communities will typically face barriers that limit their access to medical care in general and well-child care in particular. These barriers include limited or no insurance coverage, lack of a regular source of care, and lack of transportation to office visits.<sup>[24,25]</sup> Schuster et al<sup>[25]</sup> demonstrated that these barriers could be overcome using case management strategies that reach out, anticipate and learn about the needs of a community in order to effectively overcome these hurdles. In her model, these interventions came at a high monetary cost. Our model demonstrated that by

using existent hospital infrastructure, an inexpensive, comprehensive approach can be set up that allowed this high-risk population to effectively overcome local barriers to care.

Our findings support that a low cost, practical model of an effective comprehensive follow-up clinic allows for better healthcare utilization in high risk, socially disadvantaged VLBW populations by reducing the need for unplanned and costly urgent care and emergency room visits.

The main limitation of this study is that our results are based on retrospective data collected over a relatively short period of time. Another potential limitation is the use of healthy infant controls due to the lack of an appropriately matched VLBW control group, as all VLBW infants leaving our NICU were seen in the SCC.

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**Competing interest:** None declared.

**Contributors:** Waruingi W proposed the study and wrote the first draft. Iyer S analyzed the data. All authors contributed to the design and interpretation of the study and to further drafts. Collin M is the guarantor.

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