



Health Problems and Health Services Utilization of Infants Born Prematurely in the U.S.*

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=Abstract =

Purposes: The purposes of this study are to describe the health problems experienced by VLBW premature infants and their health care services utilization during the first year of life **Method:** Eighteen mothers of VLBW premature infants completed a survey questionnaire, asking socioeconomic/demographic information, health/developmental problems experienced by their infants, and their use of health care services. **Results:** Of the 18 infants, 78% experienced respiratory problems such as cold/running nose and wheezing during the first year and 33% experienced gastrointestinal problems such as vomiting, diarrhea and constipation. Twelve (67%) infants visited the emergency department at least one time and 10 infants (56%) were hospitalized at least once during their first year of age. Interestingly, infants without chronic lung disease visited the emergency department more than infants without chronic lung disease ($p=.213$). Infants living in non-disadvantaged neighborhoods were hospitalized more than infants living in disadvantaged neighborhoods ($p=.000$). **Conclusions:** Health care providers should initiate educating mothers, particularly those living in disadvantaged neighborhoods, about post-NICU discharge health care needs of their VLBW premature infants while their infants were still in the NICU so that unnecessary visits to the emergency department and rehospitalizations can be possibly prevented.

Key words : Premature infant, Health problem, Health service, Utilization

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INTRODUCTION

Infants born very prematurely (<32 weeks in gestation) or with a very low birth weight (VLBW) (<1500gm) often continue to experience medical and developmental problems post-discharge from neonatal intensive care units (NICUs) (Schariti, Hoube, Lisonkova, Klassen, & Lee, 2007; Bucher, Killer, Ochsner, Vaihinger, & Fauchere, 2002). During early childhood, premature infants are more likely to experience acute or chronic respiratory and gastrointestinal problems than full-term infants (Jackson, Schollin, Bodin, & Ternstedt, 2001). These health problems lead to a higher incidence of health care utilization including clinic and emergency room visits (Brooks-Gunn, McCormick, Klebanov, & McCarton, 1998). In addition, the literature reports higher rates of readmission to the hospital for premature infants than for full-term infants (Cuevas, Silver, Brooten, Youngblut, & Bobo, 2005). Premature infants are also at higher risk for sensorineural and developmental problems (Bucher et al., 2002). The incidence of cerebral palsy is 14.2% in infants who were born prematurely between 20 and 27 week's gestation (Robertson, Watt, & Yasui, 2007). Hearing loss is also reported to be 13.8% in conductive type and 1.5% in sensorineural type among VLBW infants (Veen et al., 1993). Indeed, VLBW premature infants constitute a vulnerable population that requires comprehensive follow-up care even after NICU discharge.

In general, the rate of children's use of health care service is associated with the socioeconomic status of the family (Simpson et al., 2005). Children from poorer families are more likely to be hospitalized and to have more emergency department visits than are children from wealthier families (Simpson et al., 2005; Brooks-Gunn et al., 1998). Socioeconomic status of the community in which the child lives is also known to affect the child's use of health care service. Children living in poor neighborhoods make more emergency department visits than children living in wealthier neighborhoods do (Boorks-Gunn et al., 1998). However, little is known about the health problems and patterns of health care service use by VLBW premature infants living in disadvantaged neighborhoods in terms of socioeconomic status. In fact, these infants belong to a group who do not comply with follow-up care appointments (Barnickol, Hirschman, & Justicz, 2005), and, thus, information regarding the health

status post-NICU discharge is rare. The purposes of this study are to describe maternal report of health and developmental problems of the VLBW infants; to assess the number and type of health care service utilization of those infants during the first year of life and to compare the health care service utilization of infants living in disadvantaged neighborhoods with that of infants in non-disadvantaged neighborhoods.

LITERATURE REVIEW

In the United States, the rate of premature births (<37 weeks' in gestation) has steadily increased over the past few decades (Martine et al., 2007). It was reported to be 10.6% in 1990, 12.0% in 2002, and 12.7% in 2005. However, substantial disparities in the birth rate of premature infants exist across different populations (Arias, MacDorman, Strobino, & Guyer, 2003). The rate of African American premature birth in 2004 was 17.8% Native Americans, 13.2% Hispanics, 12% whites, 11.5% and Asians 10.4%. The disparities in the birth of an infant with a low birth weight (< 2500gm) is even greater. About 13.5% of African American infants are born with a low birth weight, while only 7.9% of infants of all races are born with a low birth weight. African-American are the highest risk group for premature and low birth weight infant birth.

Premature infants are at greater risk for sensorineural developmental problems such as cerebral palsy, hearing and vision impairment, and cognitive and emotional problems than full-term infants (Theunissen et al., 2000; Foulder-Hughes & Cooke, 2003). These developmental problems require physical and occupational therapy, audiologists, speech and language pathologist during childhood (Bucher et al., 2002). Premature infants utilize community health care services twice as often during the first year of life when compared with full-term infants (Jackson et al., 2001). These increased use of health care services persist throughout childhood up to 8~9 years (Stevenson, McCabe, Pharoah & Cooke, 1996).

In addition to having developmental problems, premature infants often continue to suffer respiratory problems, such as bronchiolitis (wheezing), respiratory syncytial virus (RSV) infection, pneumonia, and asthma after they are discharged (Doyle, Ford, & Davis, 2003). These respiratory problems are more common in infants born with immature lungs and treated with long-term mechanical ventilatory support in the NICU. Other medical complications commonly experienced by

premature infant include anemia, apnea, gastro-esophageal reflux, feeding difficulties, and failure to thrive (Ritchie, 2002). Some of these health problems require immediate medical attention as well as routine well-care check-ups. About 25~50% of premature infants are rehospitalized during their first year of life, compared with 8~10% of full-term infants (Jackson et al., 2001). About 35% of VLBW infants are hospitalized during the first two years of life, more than the 20% of full-term infants (Bucher et al., 2002). The total duration of hospital admissions for infant born at 28-31 weeks' gestation is 16 times that for full-term infants (Petrou et al., 2003).

The most common cause of rehospitalization for premature infants is respiratory disorders, including acute bronchitis, RSV infection, pneumonia, and asthma (Doyle et al., 2003). Premature infants with chronic lung disease (CLD) (defined as those on oxygen >28days in the NICU) are particularly susceptible to respiratory infection and incur significant morbidity and mortality following hospitalization (Greenough et al., 2004). Infants with CLD had more days of readmissions for respiratory problems during the first 18 months of life (Gregoire, Lefebvre, & Gloreius, 1998). Once those infants are readmitted they tend to have a longer length of stay than full-term infants and more use of ventilators (Slonim, Patel, Ruttimann, & Pollack, 2000).

The increased use of health care services during early childhood is associated with significant medical cost (Petrou et al., 2003). The differential in the first-year medical costs between VLBW infant and all infants in the U.S. is reported to be 24 fold (Cuevas et al., 2005). Consequently, following their initial discharge from the NICU, premature and low birth weight infants can result in substantial costs to the health sector (Petrou, Sach, & Davidson, 2001).

Disparities in infant health outcomes have been observed among different socioeconomic statuses (Phares et al., 2004; Theunissen et al., 2000). Infants of younger mothers and from a lower socioeconomic status have more health problems than infants of older mothers and from a higher socioeconomic status. The risk of developmental disabilities in premature infants is also reported to increase when infants are born into families in poor socio-environments. Infants from poorer families are more likely to be hospitalized and to have more emergency department visits than infants from wealthier families in the U.S. (Brooks-Gunn et al., 1998).

In the U.S., health insurance has a great impact on children's access to primary care (Flores & Tomany-Korman, 2008). The health insurance type (e.g., public or private insurance, HMO or PPO) limits, or in some cases dictates, the physicians, hospitals, and medical services that the insurer can choose. Children with public insurance may have more limited access to routine preventive care in physician's offices, resulting in an overdependence on emergency departments and nonurgent emergency visits (Luo, Liu, Frush, & Hey, 2003). Other factors, such as family income and ethnicity, which are partly related to health insurance status, may account for the difference in the rates of health care utilization. For example, poor families residing in poor neighborhoods may have fewer doctors' clinics that are available, a lack of convenient transportation, and a need to travel through dangerous neighborhoods.

Parker, Greer, and Zuckerman (1988) used the term "double jeopardy" to describe the effect of poverty on children's health outcome. First, children from a lower socioeconomic status are more likely to be exposed to such risks as medical illness, family stress, inadequate social support, and parental depression. Second, they experience more serious consequences from these risks than do children from higher socioeconomic statuses because these risks generate the "synergistic double jeopardy" of increased exposure to and greater sequelae from environmental risks that predispose the infant to adverse developmental outcomes. Thus, in order to better understand the health outcomes of VLBW infants living in disadvantaged area, the study is designed to describe health problems experienced by VLBW premature infants living in a disadvantaged neighborhood and their use of health care services.

METHODS

Design

A descriptive, exploratory mail survey was used to describe health problems experienced by VLBW infants and their health care service utilization during the first year of life. The mothers of premature infants were asked to answer the questionnaire and return the completed survey.

Sample and Setting

To be eligible, mothers had to have infants who were born with a birth weight <1500gm or prior to 32 weeks' gestation for the period of July 2003 through August 2004 and hospitalized in the NICU at a community hospital located in a large Midwestern city in the U.S. This hospital provides medical and social services for diverse communities, including African American, Caucasian and Hispanic populations. The NICU admits approximately 500 high-risk infants annually and, among them, about 100 infants who are born less than 32 weeks' gestation or <1500gm. Infants who expired during their NICU hospitalization were excluded from the study. A total of 97 infants were identified to meet the criteria from the admission-records database, and their addresses were retrieved to mail the survey questionnaire to their mothers. Of 97 infants, 64 were African American (65.9%), 30 were Hispanic American (30.9%), and 3 were Caucasian (3%). According to an examination of the postal codes, 55% of the eligible infants' families were found to live in disadvantaged neighborhoods. The index of the neighborhood disadvantage score (Ross & Mirowsky, 2001) was computed as follows:

$$\text{INDS} = (P/10 + F/10) - (C/10 + O/10)$$

P: % of households with income below the federal poverty thresholds

F: % of female-headed households with children

C: % of adults over the age of 24 with college degrees

O: % of housing units that are owner occupied (from the U.S. Census 2000)

A neighborhood is considered disadvantaged if INDS >0 and not considered if INDS=0 or <0.

Survey Questionnaire

The survey questionnaire was developed particularly for this study to identify the health problems premature infants might possibly experience during infancy and health care service utilization. It consisted of three sections: the first section requested demographic and socioeconomic information about the mother such as race/ethnicity, age, marital status, education levels, occupation, and household income, the second section asked about the health and developmental problems of premature infants- respiratory problems such as cold/runny nose, bronchiolitis, pneumonia, asthma, and gastro-intestinal

problems such as diarrhea/constipation and vomiting, the third section included questions regarding the type of health care service that the infant used; all doctor's office visits, hospital outpatient visits, emergency department visits, and hospitalizations. In addition, any difficulties to obtain the routine well-care check-up such as transportation, insurance, and employment problems were asked. The survey questionnaire packet had a cover letter that explained the purpose and importance of the study followed by the six-page questionnaire and a consent form. The questionnaire was translated into Spanish. It was anticipated that it would take 15~20 minutes to complete.

Data Collection

After IRB approval was received, a 97 questionnaire packet was mailed to the eligible mothers twice, once in August and again in October 2005. Mothers were instructed to return the completed questionnaire in a sealed envelope addressed to the investigator. Once a mother returned the completed survey, her infant's neonatal medical history during hospitalization in the NICU was obtained from NICU medical records, including gestational age, birth weight, Apgar scores, perinatal illnesses such as CLD, brain injury, retinopathy of prematurity (ROP), and the length of NICU stay.

Data Analysis

The socioeconomic and demographic characteristics of the mothers and infants were presented using descriptive statistics. The health problems and the type and frequency of health care service utilization were summarized with descriptive statistics and a chi-square analysis compared between infants living in disadvantaged neighborhood and infants living in non-disadvantaged neighborhood in their utilization of emergency department and hospitalization.

RESULTS

Out of a total 97 survey questionnaire sent to the eligible mothers, 22 surveys (22.7%) were returned to the investigator because of address changes (moved to another place) or inaccurate addresses. Twenty completed questionnaire were received but two questionnaires were incomplete. Thus, final 18 completed questionnaires were used for data analysis.

Socioeconomic and Demographic Characteristics of Mothers and Infants

There were 14 (78%) African American infants and 4 (22%) Hispanic American infants. The birth weights of the infants ranged from 535 gm to 1550 gm, with a mean of 1142gm. The gestational ages of the infants at birth were between 24 and 33 weeks, with a mean of 28.3 weeks. The length of NICU stay ranged from 10 to 109 days, with a mean of 49.1 days. Six infants out of 18 infants were diagnosed with CLD while in the NICU. Two infants were diagnosed with intraventricular hemorrhage (IVH) and 4 infants were diagnosed with a ROP. (See Table 1)

The ages of mothers at delivery ranged from 14 to 35, with a mean age of 23.7. Most mothers were single mothers (78%) and not employed (72%). Eight mothers (44%) did not graduate high school, and 15 mothers (83%) reported their household income less than \$10,000. Most infants (83%) were receiving public insurance. By the Index of Neighborhood Disadvantage Scores, 12 mothers (66.7%) lived in disadvantaged neighborhoods while 6 mothers did not.

problems at least once during their first year: cold/runny nose, wheezing, asthma, and RSV infection. The most commonly reported respiratory problem was cold/runny nose, followed by wheezing. Surprisingly, one third of the infants in the study experienced an RSV infection although immunized with preventive vaccination before NICU discharge. As stomach/gastrointestinal problems, vomiting (33%), diarrhea (28%),and constipation (28%) are reported to be common gastrointestinal problems experienced by premature infants during their first year. Thirteen infants (72%) had had a fever (>101F) during their first year of life. Two infants reported allergies, although the type was not specified. One infant had had hernia repair and another infant underwent eye surgery before they reached one year.

Four infants (22%) had motor developmental problems, such as difficulties with crawling and walking. Three infants had hearing problems while only one infant had a vision problem. Each of four infants received care from eye or hearing specialists. Eight infants (44%) received both physical and occupational therapy, and 5 (28%) infants received early intervention service. (See Table 2.)

Health Problems

Fourteen infants (78%) experienced the following respiratory

Health Care Utilization

Of these infants, 44% followed their well-child care

<Table 1> Socioeconomic and demographic characteristics of infants and mothers

Variable			Disadvantaged area (n=12)	Non disadvantaged (n=6)	Total (n=18)
Infant	Gender	Male	4(33%)	4(67%)	8(44%)
		Female	8(67%)	2(33%)	10(56%)
	Birth weight (gm)	Mean(SD)	1,082(331)	1,262(329)	1,142(332)
	Gestational age at birth (week)	Mean(SD)	27.7(3.0)	9.5(2.7)	28.3(3.0)
	Race/ethnicity	African	9(75%)	3(83%)	14(78%)
		Hispanic	3(25%)	1(17%)	4(22%)
Length of NICU stay (days)	Mean(SD)	49.7(24.0)	8.0(35.9)	49.1(27.6)	
CLD		4(33%)	2(33%)	6(33%)	
Mother	Age	Mean(SD)	24.1(5.9)	3.1(4.4)	23.7(5.2)
	Education levels	<high school	6(50%)	2(33%)	8(44%)
		>high school	6(50%)	4(67%)	10(56%)
	Marital status	Single	8(67%)	6(100%)	14(78%)
		Married	4(33%)	0(0%)	4(22%)
	Employment status	Employed	3(25%)	2(33%)	5(28%)
		Not -Employed	9(75%)	4(67%)	13(72%)
	Household income	<\$10,000	10(83%)	5(83%)	15(83%)
		>\$10,000	2(17%)	1(17%)	3(17%)
	Insurance	Public aid	9(75%)	6(100%)	15(83%)
Private		2(17%)	0(0%)	2(11%)	

Note: CLD=Chronic Lung Disease

<Table 2> Health problems and use of health care services

Variables		Disadvantaged area (n=12)	Non-disadvantaged area (n=6)	Total (n=18)
Respiratory problems	Cold/runny nose	6 (50%)	4 (67%)	10 (55%)
	Wheezing	5 (42%)	4 (67%)	9 (50%)
	Asthma	1 (8%)	2 (33%)	3 (17%)
	Bronchiolitis	3 (25%)	0 (0%)	3 (17%)
	RSV infection	2 (16%)	4 (67%)	6 (33%)
Gastrointestinal problems	Vomiting	2 (16%)	4 (67%)	6 (33%)
	Diarrhea	2 (16%)	3 (50%)	5 (28%)
	Constipation	4 (33%)	1 (16%)	5 (28%)
	Dehydration	1 (8%)	0 (0%)	1 (6%)
Miscellaneous	Fever (>101F)	10 (83%)	3 (50%)	13 (72%)
	Allergies	0 (0%)	2 (33%)	2 (11%)
	Hernia surgery	0 (0%)	1 (16%)	1 (6%)
	Eye surgery	0 (0%)	1 (16%)	1 (6%)
Developmental problems	Hearing	0 (0%)	3 (50%)	3 (17%)
	Vision	1 (8%)	0 (0%)	1 (6%)
	Motor	1 (8%)	3 (50%)	4 (22%)
Health care system use	Physician's office	11 (92%)	5 (83%)	16 (89%)
	Outpatient clinic	10 (83%)	4 (67%)	13 (72%)
	Emergency room	9 (75%)	4 (67%)	13 (72%)
	Hospitalization	4 (33%)	4 (67%)	8 (44%)

check-up schedules in high risk clinics while 44% received their well-child care check-ups in the pediatric clinic of the hospital. The most common reason for not receiving the routine well-child care check-ups in high risk clinics was transportation problems, followed by mother's employment status, and inconvenient times.

All but two infants (89%) had visited a doctor's office in the community at least once during the first year of life. Of these, 7 infants visited more than three times. Thirteen infants (72%) visited the hospital out patient clinic at least once and 7 infants visited twice. Thirteen infants (72%) visited the emergency department at least one time, and 7 infants made two visits. Eight infants (44%) were hospitalized at least once during their first year of life. (See Table 2). Infants with CLD were hospitalized more frequently than infants without CLD

(67% vs. 33%), but less emergency department visits (67% vs. 75%) $\chi^2(df=1)=23.1, p=.000$ and $\chi^2(df=1)=1.55, p=.213$, respectively) (See Table 3). Infants living in disadvantaged neighborhoods more visited emergency department than infants living in non-disadvantaged neighborhoods (75% vs. 67%), but were less hospitalized (33% vs. 67%) $\chi^2(df=1)=1.55, p=.213$ and $\chi^2(df=1)=23.1, p=.000$, respectively) (See Table 4).

DISCUSSION

Although the sample size was small, this study provides some valuable information about VLBW infants living in disadvantaged neighborhoods. These infants are considered to be a very vulnerable group, at high risk for adverse health outcomes and frequent use of health care services after NICU

<Table 3> Use of health care system of infants with CLD and infants without CLD

	With CLD (n=6)	Without CLD (n=12)	χ^2 (df=1)	p
Emergency department	4 (67%)	9 (75%)	1.55	.213
Hospitalization	4 (67%)	4 (33%)	23.1	.000*

* p<.05; CLD: Chronic Lung Disease

<Table 4> Use of health care systems of infant living in disadvantaged and non-disadvantaged neighborhood

	Disadvantaged (n=12)	Non-disadvantaged (n=6)	χ^2 (df=1)	p
Emergency department	9 (75%)	4 (67%)	1.55	.213
Hospitalization	4 (33%)	4 (67%)	23.1	.000*

* p<.05

discharge. First, respiratory problems, such as cold/runny nose and wheezing, are the most commonly experienced health problem by VLBW infants living in disadvantaged neighborhoods during the first year of age. These findings are consistent with other studies of premature infants (Dolye et al., 2003; Bucher et al., 2002). Gastrointestinal problems, such as vomiting, diarrhea, and constipation, were also reported in about one third of the infants studied. In this study, 72% of infants were reported to have had a fever (>101F), which is consistent with the finding of 70% in Bucher's (2002) study. Thus, health problems of premature infants born to families residing in socioeconomically disadvantaged area are not very different from those of premature infants born to regular families.

Compared to Caucasian infants, African American and Hispanic infants are reported to be least likely to receive the routine well-child care (Ronsavill & Hakim, 2000). However, most infants (88%) in this study received their routine well-child check-ups either in high risk follow up clinics or pediatric clinics of the hospital. This might be explained by that mothers who complied with routine appointments were more likely to take part in the study. Some of the mothers in this study reported that lack of public transportation and inconvenient appointment times were barriers to comply with follow-up appointments.

This study found 72% of the infants studied visited emergency department at least once during their first year. This is slightly higher than the rate previously reported in the literature (27%~78%)(Cuevas et al., 2005; Dolye et al., 2003; Jackson et al., 2001; Greenough et al., 2004). In addition, 44% of the infants were readmitted at least one time which was also higher than the data reported in the literature (20~40%)(Cuevas et al., 2005; Leijon, Finnstrom, Sydsjo, & Wadsby, 2003). In the study by Cuevas and associates (2005), 60% of the infants born at less than 28 weeks' gestation and 14% of infants born at 29 weeks through 32 weeks were rehospitalized during the first year of life. The reason for rehospitalization in this study was not asked, however, Doyle and associates (2003) found that the main reason for readmission for premature infants was respiratory illness. The most common health problem reported in this study was also respiratory problems including RSV infection. However, maternal report on RSV infection of the child was not verified by health professionals. It is interesting to find that infants without CLD

more visited emergency department than infants with CLD, although it is not statistically significant. This pattern may account for characteristics of infants living in low income families and low income neighborhoods. They tend to make non-necessary visits to emergency department or the emergency department is a routine to seek medical assistance (Brooks-Gunn, et al., 1998).

Although infants living in poor neighborhoods are reported to be more frequently hospitalized, infants living in non-disadvantaged neighborhoods in the study are more often hospitalized than infants living in disadvantaged neighborhoods ($p=.000$). The INDS was used to differentiate between disadvantaged and non disadvantaged neighborhoods, however, the effect of family income and insurance status of the infant may have confound the neighborhood effect on utilization of health care in infants. Actually, the income status of sample was not significantly different between disadvantaged and non-disadvantaged neighborhoods. It will be important to investigate in the future the effect of family income as well as neighborhood income on utilization of health care in premature infants.

The adverse sequelae of premature birth are likely to have considerable long-term economic consequences for the health services and for society as a whole. Interventions to improve the health status of premature infants after NICU discharge may reduce the cost of health care use. Most of the infants studied were covered by the public insurance, and by reducing the emergency visits and rehospitalization rate, the cost of health care use in the public health budget can be reduced. Future study is needed to develop an intervention targeting premature infants who are born to low-income family living in socioeconomically disadvantaged neighborhoods.

Limitations of the study include the following. First, the information was obtained from mothers' self-reports rather than actual physician and hospital records. Mothers were asked to recall the events or health histories of their infants during the past year, thus, the validity of data has to depend on memory of mothers. Second, the responses of mothers who completed the study questionnaire may have a selection bias. Nothing is known about the infants whose mothers did not fill out questionnaire. In addition, 22.6% of the questionnaires were returned because of inaccurate addresses might cause another selection bias. Inaccurate addresses reflect that families with low incomes move frequently and, thus, it is difficult to

follow-up on the infants' health status after NICU discharge.

CONCLUSIONS

Premature infants born to mothers who have low incomes and living in disadvantaged areas require further comprehensive follow-up care not only for adverse developmental outcome but the unnecessary use of health service through unscheduled emergency room visits and hospitalizations. The results of this study provide an insight into developing an intervention program focusing on mothers whose infants are at greatest risk for adverse health outcomes. Education for the mothers of premature infants should include long-term health care needs and their management as well as immediate health care after discharge from the NICU. The data may be of value when deciding the type of resources that will be needed by these premature infants living in disadvantaged neighborhoods to prevent inadequate health care utilizations.

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