
Risk Status for Dropping Out of Developmental Followup for Very Low Birth Weight Infants

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Synopsis

Not keeping scheduled visits for medical care is a major health care issue. Little research has addressed how the interaction of demographic and biomedical parameters with psychosocial processes

has an impact on appointment keeping. Typical factors are stress of daily living, methods of coping, social support, and instrumental support (that is, tangible assistance).

In this study, the authors examine the role of these parameters and processes in the risk status for dropping out of a developmental followup program for very low birth weight infants. The findings suggest that the stress of daily living is a significant predictor for the mother's return when the infant is 6 months of age (corrected for prematurity). The predictors for return at 24 months corrected age include marital status, race, gestational age of the infant, maternal intelligence, and efficacy expectations. Providing transportation was found to be a successful intervention strategy for a subgroup at very high risk for dropping out due to a constellation of biomedical, demographic, and psychosocial factors.

IN PEDIATRIC HEALTH CARE settings, 20–50 percent of patients do not keep scheduled appointments (1). Unkept appointments result in less than optimal health care for the consumer, increased cost for the provider, and sample attrition problems for the researcher.

Characteristics associated with increased risk for adults not keeping appointments include nonwhite race, young age, low socioeconomic and educational levels, history of missed appointments, and distance from the health care site (2–5). Type of appointment is also a factor. There is an increased risk for missed appointments for nonurgent or screening visits compared with acute care or chronic illness visits (2,6,7).

Interventions to increase the rate of appointment keeping have primarily focused on use of incentives, relationship building, and reminders; these incentives have met with mixed success. For example, use of prize coupons increased the rate of appointment keeping by 13 percent in a pediatric allergy clinic (8), and use of infant formula coupons increased appointment keeping among young,

minority mothers (9). In terms of relationship building, a pre-discharge visit by a nurse practitioner increased the rate of appointment keeping by 32 percent at a post-partum clinic (10), and seeing the same physician for sequential visits was positively correlated with appointment keeping in low-income, primarily black, patients (11). Telephone reminders improved appointment keeping for patients who owned phones (12).

A limitation of the efforts to enhance appointment keeping has been the focus on demographic parameters and financial inducements as opposed to functional and process parameters that could be salient targets for intervention. That is, there has been little attention to delineating the role of processes of daily living—such as stress, coping, and social and instrumental support—in appointment keeping.

For this project, we assess how demographic parameters and biomedical and psychosocial processes act together in appointment keeping for developmental followup visits for very low birth weight infants (13). In addition, the impact on

Table 1. Number of followup examinations completed and reasons for attrition and exclusion of 207 eligible infants

Reason	Birth	6 months examination	24 months examination
<i>Excluded</i>			
Infants who died	9	¹ 12	² 26
Mothers who were not asked to participate in followup . . .	6
Mothers who refused to participate in followup	24
Infants born later	23
Mothers who withdrew	³ 3	...
<i>In study</i>			
Examination completed:			
In clinic	103	87
At home	2	3
At hospital	15	...
Missed 3 consecutive appointments or lost to study	10	34
Total in study	145	130	124

¹Died before 6 months.

²Died before 24 months.

³Withdrew before 6 months.

appointment keeping of instrumental support in the form of transportation for the developmental follow-up visits is assessed.

Method

Subjects. The subjects for this study were participants in a longitudinal developmental followup project for very low birth weight (VLBW) infants. Because the project sought to address the impact of premature birth, exclusion criteria included infants with major congenital anomalies or identifiable syndromes. During the study period July 1, 1986, to August 15, 1989, 207 infants were born at Duke Medical Center who met the eligibility criteria of birth weight of less than 1,500 grams and parent residence in a 10-county catchment area. For this study, the mothers of multiple births were included only once and the data from the later born twins or triplets were eliminated.

Table 1 presents the reasons for attrition and exclusion and followup examinations completed through 24 months of the infant's corrected age. The reasons that six mothers of eligible infants were not invited to participate included (a) two placed their babies for adoption, (b) one did not visit her infant, and (c) three had no project staff available. The reasons that 24 mothers refused to participate included (a) 11 were not interested, (b) 3 did not think it was necessary, (c) 3 were relocating out of State, (d) 2 believed they were too busy, and (e) 5 provided no reason. The reasons offered by the three mothers who withdrew before the 6

months examination were (a) two believed that followup was not necessary because their babies were doing fine, and (b) one said that an earlier examination had made the baby sick.

Demographic and biomedical characteristics of the 130 participants who were eligible for the developmental followup examinations at 6 months corrected age are presented in table 2.

Procedures. The Institutional Review Board approved the study protocol. It included demographic, biomedical, and psychosocial measures that were obtained during the infants' stay in the Neonatal Intensive Care Unit (NICU) and subsequently during developmental followup visits at 6, 15, and 24 months corrected age.

Three steps were taken to foster continued participation in the project. First, efforts were made to bond mothers to project staff starting with the invitation to participate in the project and visits with the mother during her infant's stay in the NICU. Second, parents were provided the findings from the developmental, medical, and speech and language assessments. Third, transportation, if it was a barrier to appointment keeping, was provided to and from the clinic.

The nurse coordinator (A.C.) scheduled developmental followup visits for project participants by mail or telephone. If a mother was reluctant or hesitant to schedule an appointment, the nurse asked whether transportation was needed. If the mother said yes, transportation was provided. The criteria for study dropout was failure to keep three consecutive appointments.

Demographic parameters. Demographic variables (table 2) included those that are recognized as potentially related to children's functioning or maternal adjustment, or both; maternal age, intelligence, marital status, and socioeconomic status (SES). Maternal intelligence was assessed through the Peabody Picture Vocabulary Test (14). Socioeconomic status was assessed through the Socioeconomic Index of Occupations (15) and the two-factor index of social position based on education and occupation (16). These SES indexes were calculated for each parent, and the highest level obtained was adopted as the measures of SES.

Biomedical parameters. In addition to birth weight and gestational age, which were recorded at the time of birth, the primary measure of the infant's status during the NICU stay was the neurobiologic risk score (NBRs). The NBRs was developed as a

dynamic measure of potential impact of neonatal illness on subsequent outcome (17). The NBRS is based on two premises: to alter the infant's subsequent development, a neonatal medical event must have the potential to cause cell injury and the duration and number of adverse events are important determinants of injury. Cell injury was hypothesized to occur predominantly through four mechanisms: hypoxemia, insufficient blood flow, inadequate substrate for cellular metabolism, or direct tissue damage. The severity and duration of adverse events were rated by geometric progression of scores within each of 13 items. This scoring system proved to be simple, highly reliable, and strongly predictive of developmental outcome through 24 months of age (17).

Psychosocial processes. Consistent with the underlying stress and coping model, three types of maternal psychosocial processes were included on the basis of having the potential to influence maternal psychological adjustment and the infant's development: cognitive processes of appraisal of stress and expectations of efficacy, methods of coping, and social support in terms of the family's functioning. These maternal psychosocial processes were assessed at birth and at each subsequent developmental followup visits. The data from the assessments at birth were used in this study. Staff assisted mothers who had difficulty reading and interpreting the various questionnaires.

Cognitive processes. Daily stress was assessed with the 117-item Hassles Scale (18) that yields a measure (sum) reflecting both frequency and severity ratings. The items reflect irritants that range from minor annoyances to fairly major pressures, problems, or difficulties that characterize everyday transactions with the environment. Each item is rated as whether it happened during the previous month and, if so, how severe it was (on a scale of 1 to 3).

A structured interview, conducted by a psychologist, was utilized to assess maternal appraisal of stress and expectations of efficacy in relation to three illness-related tasks (19): (a) dealing with the babies' symptoms and treatments, (b) maintaining their own emotional well-being, and (c) preparing for an uncertain future. Mothers rated how stressful, from 1 (not stressful at all) to 100 (very stressful) and her confidence level, from 1 percent (great uncertainty) to 100 percent (complete certainty) for each of the three tasks. Stress and efficacy sum scores were then obtained across the three tasks.

Table 2. Mothers' demographic and infants' biomedical parameters of the study sample of 130 very low birth weight infants

Variable	Measure		Number	Percent
	Mean	Standard deviation		
Infants:				
Birth weight (grams)	1,114.3	262.3
Gestational age (weeks) ..	28.7	2.6
First born	72	55.4
Male	62	47.7
Nonwhite	90	69.2
Mothers:				
Age (years)	25.2	5.7
Peabody intelligence quotient score	84.2	19.0
Married	73	56.2
Rural residence	63	48.5
Socioeconomic status:				
Level I (high)	8	6.2
Level II	14	10.8
Level III	22	16.9
Level IV	53	40.8
Level V (low)	33	25.4
Education (years)				
Less than high school	12.3	2.3	39	30.0
High school	45	34.6
More than high school	46	35.4

Methods of Coping

The ways of coping questionnaire (20-22) consists of 65 items describing coping behaviors. Mothers were instructed to indicate on a five-point scale how often (never, seldom, sometimes, often, most of the time) they used each coping behavior in relation to the overall situation of caring for their VLBW infant. Factor analytic studies have delineated both broad band methods of coping, such as emotion focused and problem focused (20), and specific subtypes (21,22). Palliative coping is the sum of the item scores that comprise the emotion focused, avoidance, wishful thinking, and self-blame factors. Adaptive coping is the sum of the item scores constituting the problem focused, cognitive restructuring, seeking information, and seeking social support factors. The Cronbach Alpha was .87 for palliative coping and .91 for adaptive coping. A coping ratio score (22) was also derived (palliative coping ÷ palliative + adaptive coping).

Social Support and Family Functioning

The Family Environment Scale (FES) (23) consists of 90 true-false items that form 10 subscales. Three higher order FES factors were delineated and

Table 3. Comparison of 87 infants who returned for the examination and 34 who did not complete the 24 months examination

Variable	Completed examination		χ^2	df	F
	No	Yes			
Demographic:					
Nonwhite (percent) ..	88	60	19.07	1	...
Married mothers (percent).....	24	51	17.30	1	...
Maternal IQ (mean) ..	78.40	86.23	...	1,114	² 3.99
Biomedical: gestational age (mean weeks)....					
	29.59	28.52	...	1,119	² 4.25
Psychosocial: efficacy (mean).....					
	204.91	231.77	...	1,100	² 4.46

¹P < .01. ²P < .05.
NOTE: df = degrees of freedom.

replicated with families with chronically ill children (24). The primary dimension of interest for this study is the supportive factor, which reflects the degree of mutual commitment and support for expression of feelings and for active participation in social and recreational activities.

Maternal Psychosocial Adjustment

The Symptom Checklist 90-revised (SCL-90-R) (25) is a 90-item self-report measure of psychological distress along nine symptom dimensions. The Global Severity Index combines information on the number of symptoms and intensity of distress and provides a measure of overall level of psychological distress.

Results

Completion rates for followup visits at 6 months and 24 months of age. Table 1 presents the exclusions, completions, and attrition of developmental followup by study time. Of the 130 study participants, 103 (79 percent) returned for the developmental followup examination at 6 months of age, 17 (13 percent) had the examination completed in the hospital or at home because of the infant's poor health, and 10 (8 percent) did not complete the examination. The reasons for not completing the examination included four who moved out of State, one who was lost to followup, and five who missed three scheduled appointments.

Six infants (5 percent) died between the followup examination at 6 months and 24 months, and all 6 had been among the 17 who had their 6 months examinations completed in the hospital or at home. Of the 124 study participants eligible for the 24 months examinations, 87 returned, 3 had their

examination completed in the hospital or at home, and 34 did not complete the examination. The reasons for not completing the examination included 9 who moved out of State, 3 who were lost to followup, 6 who refused, and 16 who missed three scheduled appointments. The overall rate of dropout or attrition by 24 months of age was 31 percent ($[(34 \text{ not completing} + 6 \text{ died}) \div 130]$). None of the 10 study participants who failed to complete their 6 months examination returned for their 24 months examination (1 did have the 24 months examination completed at home).

Characteristics of Noncompleters

The 34 study participants who failed to complete their child's 24 months examination differed significantly from the 87 participants who completed the examination in terms of demographic, biomedical, and psychosocial parameters (table 3). Subgroup differences were assessed using chi-square (χ^2) for categorical data and analysis of variance (ANOVA) for metric data. The subgroup who did not complete the examination had a lower percentage who were married, a higher percentage who were nonwhite, higher gestational age, lower maternal intelligence, and lower efficacy ratings than the subgroup who completed the examination. However, there were no significant differences in SES, birth weight, or NBRS, ratings of stress regarding daily hassles or tasks associated with caring for VLBW infants, coping method, or psychological distress.

Because not completing the 6 months examination was predictive of not completing the 24 months examination, an analysis was also undertaken of the characteristics of those who returned and those who did not complete the 6 months examination. The 10 participants who did not complete the examination differed from the 103 who returned only in terms of higher maternal ratings of daily stress [M (mean) 78.57 versus 41.39, $F(1,87) = 5.61, P < .02$].

Impact of Transportation

Of the 103 study participants who returned for their 6 months examination, 32 (31 percent) were transported. Those transported differed significantly from the 71 (69 percent) who returned without being transported in terms of demographic, biomedical, and psychosocial parameters (table 4). The subgroup who were transported had a higher percentage of women who were nonwhite, a lower percentage who were married, and lower SES

Table 4. Comparison of 32 infants who were transported and 71 not transported for the 6 months examination, by mothers' demographic and psychosocial and infants' biomedical parameters

Variable	Completed examination		χ^2	df	F
	No	Yes			
<i>Demographic</i>					
Nonwhite (percent)	44	8	¹ 14.21	1	...
Married mothers (percent).....	9	91	² 27.16	1	...
Socioeconomic status (percent):	² 25.81
Levels I-III	6	49
Level IV	38	37
Level V.....	56	14
Maternal age (mean years).....	22.28	26.48	...	1,101	¹ 14.22
Maternal education (mean years)	10.59	13.07	...	1,101	² 31.75
Maternal IQ (mean).....	74.03	90.31	...	1,100	² 17.31
<i>Biomedical</i>					
Birth weight (mean grams)	1,220	1,100	...	1,101	³ 5.25
Neurobiologic risk score	4.91	8.00	...	1,101	⁴ 8.17
<i>Psychosocial</i>					
Palliative coping ratio (mean).....	0.48	0.45	...	1,94	⁴ 6.70
Family supportiveness (mean)	236.54	260.68	...	1,88	⁴ 8.26

¹ $P < .001$.

² $P < .0001$.

³ $P < .05$.

⁴ $P < .01$.

NOTE: df = degrees of freedom.

levels, maternal age, maternal years of education, and maternal Peabody IQ (intelligence quotient). The subgroup who were transported also had infants with higher birth weight and lower NBRSSs. In terms of psychosocial parameters, there were no significant subgroup differences in maternal stress or efficacy ratings or psychological distress, but the subgroup who were transported had a higher ratio of utilization of palliative coping to adaptive coping methods and family functioning characterized by lower levels of supportiveness.

Of the 32 study participants who were transported for the 6 months examination, 8 were lost to followup by the 24 months examination, yielding an attrition rate of 25 compared with 16 percent (11 ÷ 71) for those who returned without being transported [chi-square (1) = 1.32, $P < .25$]. The 87 participants who completed their 24 months examination did not differ significantly from the original study sample of 130 in demographic, biomedical, or psychosocial parameters. However, if the 24 study participants had not been maintained through transportation, the resulting study sample of 63 (87 - 24) would have been significantly different from the original sample in demographic parameters. The resulting study sample would have had a lower percentage who were nonwhite [49 percent versus 69 percent, chi-square (1) = 7.28, $P < .007$], a higher percentage who were married [65 percent versus 44 percent, chi-square (1) = 7.66, $P < .006$], higher SES (M 44.14 versus 33.84, F (1,191) = 6.29, $P < .01$), and higher maternal Peabody IQ (M 90.69 versus 84.24, F (1,184) = 4.64, $P < .03$).

Discussion

While the overall attrition rate by 24 months of age (corrected for prematurity) was 31 percent, only 5 percent was due to death. The other 26 percent was due to not keeping scheduled appointments for developmental followup visits.

SES, coping methods, family supportiveness, and maternal stress and distress were not associated with high-risk status for dropping out. However, not keeping the 6 months examination was very predictive of not returning for the 24 months examination. Mothers failing to return for the 6 months examination were characterized by very high levels of daily stress.

Thus, those at highest risk for dropping out of this VLBW developmental followup project were mothers who viewed their daily lives as stressful. Providing those at highest risk for dropping out with services that emphasize stress management techniques might be helpful in preventing missed appointments for scheduled return visits for developmental followup.

The effectiveness of providing transportation in maintaining very high-risk participants in developmental followup was clearly demonstrated. Those transported were at risk in terms of demographic parameters and also were characterized by reliance upon palliative coping methods and low family supportiveness. Not only were 32 high-risk participants included in the 6 months followup, only 8 were subsequently lost for the 24 months followup. Moreover, the impact of transportation can best be

seen in terms of the effect of attrition on study sample representativeness. The study sample of 87 who completed the 24 months examination did not differ significantly from the 130 eligible participants. However, if those who were transported had been lost to followup, the sample would have no longer been representative in terms of the demographic characteristics of SES, race, marital status, and maternal IQ. Thus, providing transportation for those who require it appears to be an effective intervention strategy.

Effectiveness of providing transportation also needs to be considered in terms of the additional cost in both the project coordinator's time and monetary expenditures. The project coordinator expended on average 2 hours per transport. Average cost for reimbursing travel and parking for participants who were not transported was \$7.82. The average cost for a round trip transport was \$11.29. While the cost of transport is higher, the major benefit is in terms of maintaining the child in the health care system.

For instance, two of the infants transported for their 6 months evaluation had not previously been served in the health care system but, during evaluation, excessive increase in head circumference coupled with developmental delay was identified. These children were subsequently linked to the health care system, diagnosed with hydrocephalus, and treated successfully. Thus, providing transportation for those at high risk for missed appointments may prove to be a cost-effective intervention in terms of fostering clinical care and representativeness of research samples.

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