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Parents of Preterm and Very Low Birthweight Infants and Their Childrearing Practices

Elizabeth A. Koldoff[1], Barbara J. Holtzclaw[1], and Thubi H. A. Kolobe[2]

Abstract

Emerging research supports that early intervention leads to better health and higher functional status for infants with very low birthweight and/or low gestational age. Optimizing the transition from neonatal intensive care to early intervention programs relies heavily on parent engagement. The purpose of this descriptive correlational study was to investigate the relationship between parental characteristics, childrearing behaviors, and participation in early intervention. We used convenience sampling of 49 parents who participated in early intervention and the Parent Behavior Checklist to assess parent characteristics. Correlation coefficients between parenting behaviors, birthweight, and participation in early intervention were low. An important finding was that most parents in this study were within the "average" range for childrearing practices, despite the documented challenges associated with very low birthweight or gestational age. Despite documented challenges, parents of preterm infants with very low birthweight and parents of typical birthweight infants have similar parenting beliefs and behavior.

Keywords

parents, very low birthweight, prematurity, early intervention

Infants born with very low birth weight (VLBW) and/or low gestational age (GA) have increased probability for motor, cognitive, and behavioral impairment leading to developmental delay. Neurologists recognize early intervention (EI) programs as essential to minimize complications that impede the child's health and function (Miller et al., 2019; Spittle et al., 2015). Infants with VLBW or low GA are eligible for EI as defined in the Individuals with Disability Education Act (2021). The definition of EI is a multidisciplinary service for children ages birth to three to promote optimal health and function of the child and their family through individualized plans for education or therapy (Shonkoff & Levitt, 2010).

Infant and Parental Factors that Influence Childhood Development

Ideally, parents are informed about EI in the neonatal intensive care unit and referrals are made upon discharge. However, there is a gap between EI referral rates and EI enrollment rates from discharge to the point of parental decision to participate (Mills et al., 2018). A child's involvement in EI programs is dependent upon parental participation, yet some studies report that only about half of parents with eligible infants participate (Roberts et al., 2008; Wang et al., 2009). Socioeconomic status, culture, and severity of disability may influence participation (McManus et al., 2013; Wang et al., 2009). Studies of parenting behavior may reveal how beliefs about childrearing influence decisions that occur between referral and enrollment.

Infant characteristics may contribute to a risk of developmental delay. Scientific advances in neonatal preterm care have increased survival rates of low GA infants with VLBW over the past two decades (Blencowe et al., 2012). Birthweight and GA are highly correlated, even as birth weight may vary widely among GAs. For example, twins can be full term with one having a significantly lower birthweight. Combining,

[1]Fran and Earl Ziegler College of Nursing, University of Oklahoma Health Sciences Center, Oklahoma City, OK, USA
[2]Department of Rehabilitation Sciences, University of Oklahoma Health Sciences Center, Oklahoma City, OK, USA

Corresponding Author:
Elizabeth A. Koldoff, Fran and Earl Ziegler College of Nursing, University of Oklahoma Health Sciences Center, 1100 N Stonewall Ave, Oklahoma City, OK 73104-5410, USA.
Email: elizabeth-koldoff@ouhsc.edu

VLBW, defined as an infant born less than 1,500 grams, with low GA, defined as less than 32 weeks, may be helpful in defining the population of this study. Low GA infants born with VLBW may be at risk for many negative outcomes, since, in addition to being physically small, these infants may also be physiologically immature (Kirkegaard et al., 2006). Complications may include hypothermia, hypoglycemia, respiratory problems, impaired nutrition, ophthalmic complications, and neurological issues. These conditions put infants at risk for a higher probability for motor, cognitive, and behavioral impairment (Spittle et al., 2015). Deficits in two or more domains such as motor skills, speech, cognition, social, or activities of daily living is defined as developmental delay (Belanger & Caron, 2018).

The Individuals with Disability Education Act protects the rights of children with, or at risk for, disabilities and their families. Part C of this federal legislation specifically addresses the needs of infants and toddlers who have, or are at risk for, physical, cognitive, communication, and social or emotional delays. Part C recommendation is that eligible children enroll in EI as part of an individualized family service plan in a natural environment. Many programs fall under the definition of EI. Most parents in this study participated in two different forms of EI: An ongoing research project testing efficacy of the innovative Self-Initiated Prone Progression Crawler (Kolobe & Fagg, 2019), and the state-sponsored birth-to-three program, Oklahoma's SoonerStart. Referral for EI occurs directly from the neonatal intensive care unit and infants are solely dependent on parental participation to reduce risk of developmental delay, underscoring the need for evidence about related factors.

The impact of medical care and developmental problems in infants with VLBW can be disruptive to the family, particularly parents. Parenting responsibilities may have increased physical and emotional demands, disrupting family and social relationships, and affecting employment and finances (Resch et al., 2010). However, studies have found that with adequate information, support, and time to modify their expectations many families adjust well and experience positive family function (Benzies et al., 2013). Identifying families, who have children at higher risk for developmental delay, is an ongoing priority for health and well-being.

Parental characteristics, such as beliefs and behavior, can reflect strengths in dealing with unexpected challenges to childrearing, as well as areas needing more support. For example, researchers have demonstrated that parent behavior and childrearing practices influence cognitive and behavioral outcomes in young children (Towe-Goodman et al., 2014). Another study supports that developmental programs have an effect on parental behavior promoting early childhood development (Shah et al., 2019). However, studies also support the need for further research about how childrearing practices affect developmental outcomes. These studies note that encouraging positive parental behavior improves child outcomes but lack the perspective and situational specifics of parents who have infants with VLBW (Shah et al., 2019; Zvara et al., 2019). Many parents of infants with VLBW are able to manage the unexpected developmental challenges very well. However, the extent to which childbearing beliefs influence engagement in early therapeutic approaches has not been explored.

Parenting perceptions seem to be closely associated with nurturing and disciplinary behaviors. For example, in a study of 2 year olds, with the majority exhibiting developmental delays, parents with high developmental expectations were more likely to practice strict discipline and lower nurturing practices (Keller & Fox, 2009). Another study with 47 participants suggested that parents of children with a language delay have lower levels of nurturing behavior and higher incidence of punitive punishment than parents of typically developing children (Carson et al., 2007). Assessing these aspects of childrearing practices for parents of infants with VLBW may be an important step leading to targeted interventions for time-sensitive programs.

Comparative studies between parents with preschool children with mild disabilities and those with typically developing children, showed no significant differences in discipline or nurturing (Tucker & Fox, 1995). The two groups did not differ significantly in discipline or nurturing. However, the parents of typically developing children had higher developmental expectations. The question remains how parents of infants with VLBW would compare to parents of typically developing infants.

The study reported here specifically included parents' developmental expectations, nurturing behavior, and discipline strategies. Developmental expectations are defined by goals that a parent would anticipate a child would accomplish. High expectations may frustrate the child, while low expectations may result in insufficient stimulation of the infant. Two approaches to assist a child in reaching developmental goals would be nurturing behavior, which tends to be more positive, and discipline strategies, which focuses on reinforcing boundaries (Arevalo et al., 2014; Fox, 1992). Because parent behavior is a major influence in the child's participation, parents play a critical role in outcomes. It remains unknown whether childrearing practices of parents and participation in EI are primary influences on outcomes of infants with VLBW. Therefore, this study focused on generating knowledge about these parental factors in the context of EI participation.

Theoretical Models

Several theoretical models, such as Barnard's Child Health Assessment Interaction model, Ainsworth's Description of Sensitivity, and the "developmental niche" model (Tryphonopoulos et al., 2016) demonstrate the link between childrearing practices and child outcomes. The consensus is that parental behavior influences child development and these models explain various factors of the complex relationship

between parent and child. The child as an active learner but puts the majority of the responsibility on the caregiver. Emphasis is also on the sensitivity of the parent and their ability to respond to the child's signals. Studies, such as Arevalo et al. (2014), reveal the influence of childrearing practices on child outcomes where a relationship was found with academic performance in school-age Mexican-American children. Given that low GA infants with VLBW may have additional challenges that influence the relationship between parent and child, how these challenges have influenced parental decisions to participation in EI is not clear. This study may provide new insights informing proactive interventions to improve recruitment to EI programs.

Purpose

The intent of this study was to investigate factors that have potential to optimize the transition from neonatal intensive care to enrollment in EI programs. The primary purpose was to answer the research question: What is the relationship between parental characteristics, childrearing practices, and participation in EI?

Methods

Design

This descriptive correlational study explored the relationship between parental childrearing behaviors and participation in EI programs for low GA infants with VLBW who are at risk for developmental delay. Of particular interest were parental behaviors affecting nurturing, developmental expectations, and discipline strategies and how the scores compared with parents who had infants with typical development. Approval of the study was received from the institutional review board at the University of Oklahoma Health Sciences Center.

A priori power analysis, using G*Power Version 3.1 (Faul et al., 2009) for correlations indicated a sample of 64 was needed to detect a medium effect size of 0.3 for an alpha level of 0.05 and a power of 80%. After an exhaustive attempt to secure an adequate sample size, 49 participants were recruited. A *post hoc* analysis for correlation determined power to be at 70%.

Sample

A convenience sample consisted of parents with infants enrolled in regional EI programs taking place in an urban community of Oklahoma. Inclusion criteria selected parents with an infant who had low or VLBW and/or low GA and were involved in EI therapeutic programs sponsored by Part C of the Individuals with Disabilities Act (i.e., Oklahoma SoonerStart Program). Eligibility for SoonerStart enrollment from the neonatal intensive care unit was VLBW and/or low GA. In addition to the state-sponsored birth-to-three program, the majority of parents were involved in another EI research project, the Self-Initiated Prone Progression Crawler (Kolobe & Fagg, 2019), that tested a device to reinforce movement and attempts to crawl. All infants in the Self-Initiated Prone Progression Crawler study were born at less than 30 weeks GA. Both programs engaged parents directly from neonatal intensive care units at two local hospitals. Snowball sampling of additional participants resulted from parent interviews and partnerships with the Oklahoma Family Network and a local parent support group.

Measures

The Parent Behavior Checklist, which consists of three subscales, measured parenting and childrearing behaviors: developmental expectations, nurturing, and discipline strategies. The Parent Behavior Checklist (Fox, 1992) was normed on parents of children with typical development who are ages one to five years. The three parental characteristics of interest in this study were developmental expectations (e.g., "My child should be able to feed him/herself"), nurturing behavior (e.g., "I read to my child at bedtime"), and discipline strategies (e.g., "I yell at my child for spilling food").

The developmental expectations subscale (12 items) assess a parent's anticipation for the developmental milestones of the child (Fox et al., 1995). The nurturing behavior subscale (10 items) assess positive actions that promote a child's psychological growth (Fox et al., 1995). Higher scores reflect constructive parenting techniques such as positive reinforcement (Fox et al., 2007). The discipline strategies subscale (10 items) assess the parent's response to problem behaviors (Fox et al., 1995). Higher scores reflect an increased level of verbal and corporal punishment, which has been linked to behavior problems in young children (Fox et al., 2007). Demographic variables were included to describe the sample and determine if any relationships exist with Parent Behavior Checklist scores.

Parent Behavior Checklist items are scored on a four-point frequency scale (4 = almost always/always, 3 = frequently, 2 = sometimes, and 1 = almost never/never). Higher scores reflect higher parental expectations, increased level of nurturing, and punitive discipline strategies. The Parent Behavior Checklist demonstrated excellent psychometric properties, demonstrated through a field test with 1,140 mothers of varying ages, marital status, socioeconomic levels from a large urban area (Fox, 1992). Alpha coefficients for the three subscales were expectations = .93, discipline = .85, nurturing = .73, and all three subscales were sensitive to the age of the child (Fox, 1992; Fox & Bentley, 1992).

A demographic questionnaire gathered family background information to describe the sample and provided characteristics to determine relationships with Parent Behavior Checklist scores. Data were collected about the parents' marital status, age, level of education, occupation,

age of the child at the time of collection, general health of the child and diagnosis if known, and number of other children in the household. EI participation was measured as a binary categorical variable of "yes" or "no."

Data Collection Procedure

Parents from the Self-Initiated Prone Progression Crawler study had previously agreed to follow-up contact for future research and were contacted by phone. Second attempts to contact were by text messaging with assistance from the therapist that worked with infant during the Self-Initiated Prone Progression Crawler study. The researcher explained study procedures to participants by phone or email. Parents, after assurance of the voluntary nature of the study, completed questionnaires in their home or a public place of their choosing. Following consent to participate, parents completed the Parent Behavior Checklist and demographic questionnaire. The first author called the parents to ask if they had questions and met with parents who needed help in completing the questionnaires.

Data Analysis

Analysis of data was completed using SPSS software (version 22). Analysis of the Parent Behavior Checklist began with exploration of raw data and calculation of descriptive statistics. Box plots identified any outlier data. Pearson's *r* and scatterplots were created to explore possible relationships between the subscales and level of education, GA at birth, race, and participation in EI.

Raw scores from the Parent Behavior Checklist were converted into *T* scores with higher scores in the expectations subscale indicated higher levels of parental standards. Higher scores in nurturing indicate higher frequency of nurturing behavior by parents. Scores that are higher in the discipline subscale indicate that it is more likely that parents use verbal and physical punishment. Fox has predetermined an arbitrary band of average *T* scores that are one and a half standard deviations from the mean *T* score of 50, thus scores between 35 and 65 would be considered "average" (Fox, 1992). Scores below the average range would be "well below average" (25–34) or "lower extreme" (20–24). Scores above the average range would be "well above average" (66–75) or "upper extreme" (76–81). Fox suggests interpreting scores in the context of other assessment findings such as education level, economic status, and developmental level of the child (1992).

The Parent Behavior Checklist provides normative scores specifically for parents of children with typical development from age one to five years. This allowed for comparisons of childrearing beliefs with parents of infants with VLBW or low GA. Because of the wide range of birthweight (450–2,500 grams), we also used GA for comparisons. Approximately 90% of parents had infants who were both VLBW and low GA.

Results

Sociodemographic Descriptive Statistics

Survey data from the questionnaires ($n = 49$) included age of parents, race, marital status, level of education, and infant age and medical status (Table 1). Most of the parents were female ($n = 47$) and were married, Caucasian, college educated, and active participants in EI. Representation of African American and American Indian parents was higher (12%) than state distribution for these races, which were about 7.5% each. State records also indicate that infants with VLBW are at 13.4 for African Americans and 7.4% for American Indians (Centers for Disease Control and Prevention, 2017). A majority the infants of participating parents were of VLBW born between 26 and 31 weeks' gestation.

Fox's Parent Behavior Checklist Subscale Findings

Table 2 depicts the mean and standard deviations for the *T* scores of Parent Behavior Checklist subscales. When compared with Fox's normative scores on all three subscales, means of developmental expectation and discipline strategies were lower than the published mean *T* score for parents of typically developing children: 50 ($SD = 10$) (Platz et al., 1994). However, they are in the average range for their child's age (*T* scores, 35–65).

Tests of Relationships

Correlations from the data answered research questions about relationships between parental characteristics, participation in EI, and childrearing. The *T* scores of Parent Behavior Checklist data were ordinally grouped using Fox's interpretation categories into "lower extreme," "well below average," "average," "above average," and "upper extreme." Frequencies were performed for *T* score interpretation (Table 3). Most parents' scores were average for all three subscales. However, a subset of about one fifth of parent scores were "well below average" for developmental expectations and disciplinary strategies.

Correlations must meet assumptions about outliers and normalcy before testing for associations between subscales of the Parent Behavior Checklist. Boxplots tested the first assumption, which revealed two outliers for the discipline strategy *T* scores. Consensus among the researchers determined these outliers would not have an effect on statistical outcomes since one was the maximum and the other was the minimum score in the range. A Shapiro–Wilk test of the data determined normal distribution (expectation subscale = .101, discipline subscale = .108, and nurturing subscale = .093). Scatterplots showed no linear association between nurturing and developmental expectations. A slight linear relationship existed between nurturing and discipline strategies. Expectations and discipline strategies also shared a linear association. Pearson's *r* correlations between nurturing

Table 1. Sociodemographic Parent Characteristics ($n = 49$).

Variable	Frequency	%
Parent age		
26–35	28	57%
36–45	21	43%
Race		
Caucasian	37	76%
African American	6	12%
American Indian	6	12%
Employment		
Not employed by choice	21	49%
Part time	11	22%
Full time	19	35%
Level of education		
High school	5	10%
College degree	34	69%
Graduate degree	11	22%
Marital status; married	45	91%
Birth weight		
Very low: less than 1,500 grams	37	75%
Low: 1,500 to 2,500 grams	8	16%
Medical diagnosis		
None	30	61%
Cerebral palsy	7	14%
Other (i.e., chronic lung disease)	10	20%

Table 2. Descriptives for Parent Behavior Checklist Subscales ($n = 49$).

Variable	Mean	*SD*	Range
PBC-E	43.02	10.98	20–63
PBC-D	40.33	6.42	28–59
PBC-N	53.42	8.63	33–68

Note. Abbreviations: PBC-E, developmental expectations subscale; PBC-D, discipline strategies subscale; PBC-N, nurturing behavior subscale.

and discipline yielded a coefficient of .103, failing to reach statistical significance. Correlations between developmental expectations and discipline scores trended toward significance, showing a mild, but positive linear relationship ($r = .283$, $p = .051$).

Pearson's r was used to analyze relationships between level of education, GA, medical conditions, race, and participation in EI. There was no apparent association between the Parent Behavior Checklist Subscales and variables such as level of education, medical conditions, race, or participation in EI. Scatterplots revealed that infant GA was positively associated with higher developmental expectations (Figure 1). Mean scores for nurturing were higher for infants with greater GA compared to infants born less than 32 weeks (Figure 2). However, one must use caution when interpreting these scores since more infants in this study were born below 32 weeks.

Table 3. Frequencies of PBC Score Interpretation ($n = 49$).

Variable	Interpretation	Frequency	%
Developmental expectations	Lower extreme	4	8
	Well-below average	8	16
	Average	37	76
	Well-above average	0	—
Discipline strategies	Lower extreme	0	—
	Well-below average	10	20
	Average	39	80
	Well-above average	0	—
Nurturing	Lower extreme	0	—
	Well-below average	2	4
	Average	45	92
	Well-above average	2	4

Discussion

This study explored the parenting and childrearing behaviors of parents of VLBW or low GA infants and their participation in EI. Infants with VLBW and low GA are at risk for developmental delay. Findings revealed previously unexamined characteristics of parents who participate in EI programs for preterm infants with VLBW. An important finding for this study was that most parents in this group had childrearing behaviors that were within the average range by child's age for all three subscales of the Parent Behavior Checklist. Because the Parent Behavior Checklist provides normative scores of a large group of parents with typically developing children, this comparison suggests that parents of low GA infants with VLBW have similar childrearing beliefs. The present study results are consistent with those from other studies. One study, comparing parents of preschool children with mild disabilities to typical children, found no differences in discipline strategies and nurturing behaviors (Tucker & Fox, 1995). In addition, studies of parents with children with chronic health conditions (spina bifida and cardiac conditions) also confirm that parenting behaviors did not differ from parents of children who were considered healthy (Carey et al., 2002; Lomax-Bream et al., 2007). These findings collectively add to the evidence that there may not be observable differences in childrearing practices between most parents of preterm infants with VLBW and parents of infants with typical birthweight and GA.

Parental response to this phenomenon may suggest reasons why nurturing scores were higher for infants. In addition, a longer time in the neonatal intensive care unit may exaggerate parents' perceptions of vulnerability (Chambers et al., 2011), explaining why infants born 31 weeks gestation or less, have lower developmental expectation scores. Findings showing that GA was associated with childrearing practices may be due, in part, to the longer period of time that infants with VLBW remain in the neonatal intensive care unit, deprived of physical contact, consistent attachment and bonding (Wigert et al., 2006).

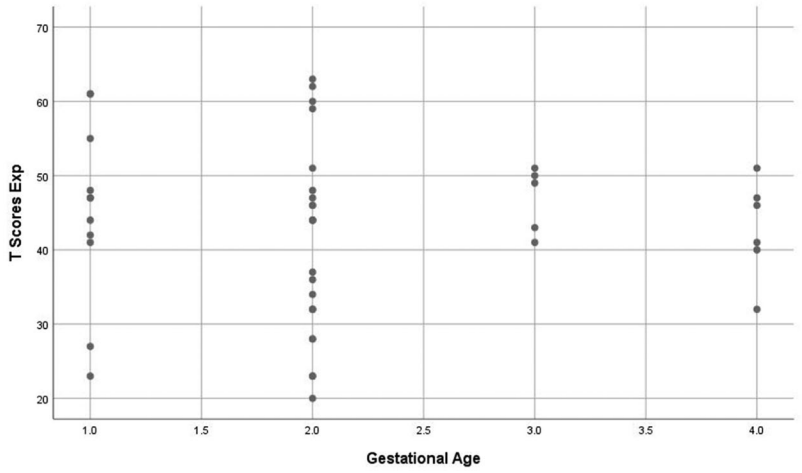

Figure 1. Association between gestational age and developmental expectations ($n = 49$). For gestational age, 1 = less than 26 weeks, 2 = 26 to 31 weeks, 3 = 32 to 36 weeks, 4 = full term. Developmental expectation *T* scores mean = 43.02, standard deviation = 10.984.

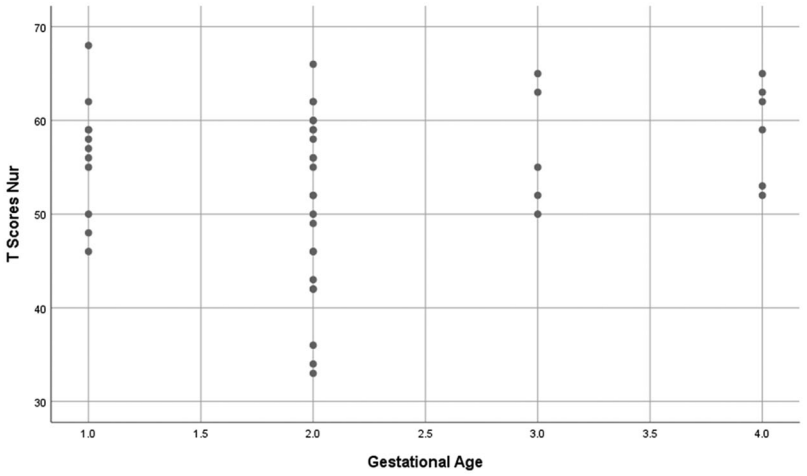

Figure 2. Association between gestational age and nurturing ($n = 49$). For gestational age, 1 = less than 26 weeks, 2 = 26 to 31 weeks, 3 = 32 to 36 weeks, 4 = full term. Nurturing *T* scores mean = 53.42, standard deviation = 8.627.

The subset of parents scoring "below average" or "lower extreme" for developmental expectations and discipline strategies bear closer attention. Findings suggest that, although the majority of parents are in the average range for childrearing beliefs and behavior, there may be individuals in greater need for support in one area or another. Low expectations or pessimistic views may influence readiness to seek intervention. Using the Parent Behavior Checklist to assess individual parenting characteristics for parents of low GA infants with VLBW may identify a need for intervention. For example, a parent who scores low in developmental expectations may need more education about child development in the context of their child's unique needs.

Findings in the current study found no evidence that there is an influence on EI participation by level of education. However, an underpowered sample size may explain why this study was unable to find an association between education and parental behaviors. The majority of parents were highly educated with most having a bachelor's degree or higher. This demographic may suggest that highly educated parents may be more likely to be aware of EI programs and their benefits, and thus more likely to participate. Other studies have documented that education and socioeconomic factors do influence, in part, parental behavior and enrollment in EI (Fox et al., 1995; Hackworth et al., 2018,). While the findings of this study do not statistically support an association

between EI and socioeconomic factors, studies that are larger and more diverse may find such evidence for parents of low GA infants with VLBW.

Findings from this study contribute to an emerging knowledge about parenting and childrearing behaviors of those participating in EI. However, there were some limitations. Although the original intent was to compare those who did and did not participate, it proved to be difficult to recruit a sufficient number of parents who did not participate in EI. Attempts by the researchers to recruit participants were rigorous, which speaks to the need to examine factors that deter or enable parents to participate in more than just EI. However, scores of the Parent Behavior Checklist are normed, based on typically developing children, which may be helpful in exploring a comparison of parents included in this study.

A small sample size was another limitation for this quantitative study. Because of the wide range of birth weight and the small sample size, we were not able to conduct inferential statistics for birthweight. Attempts to categorize the weights resulted in unequal sample distribution. In addition, characteristics such as younger parents and length of neonatal intensive care stay are associated with child outcomes (Hackworth et al., 2018) and may yield different childrearing results. The age range of parents in this study was 26–45 years. Lastly, the sample size lacked sufficient power to demonstrate statistical significance resulting in cautious interpretation.

The Parent Behavior Checklist is a self-report of parental beliefs rather than a direct measure of behavior. Although insight from the participant's viewpoint is valuable, over- or under-estimating one's perception of behavior is possible. Participants may feel pressured to give socially acceptable answers (Donaldson & Grant-Vallone, 2002; Stone & Shiffman, 2002) leading to a response bias and considered with the interpretation of results. Several parents expressed hesitancy about the word "spanking" when questioned about discipline strategies. This may have influenced the validity of answers to discipline-related items.

Despite these limitations, the findings from this study may be important to nursing as a beginning endeavor to identify characteristics that are associated with parents who participate in EI. A couple of practice recommendations for health care providers come out of these findings. (a) There was no evidence that parents of infants with VLBW had maladaptive parenting beliefs and behavior. (b) Practitioners who guide referral and care may benefit from a detailed assessment about parental characteristics and needs before their infant is discharged from acute care settings.

The results of this study also suggest some research implications. (a) Although it was possible to learn about challenges to participation from parents that were currently engaged in EI, our findings raise the question of whether these factors would characterize parents who do not participate in EI programs. Although the original intent was to question nonparticipating parents, it presented a challenge to track parents who did not participate in EI. Characteristics may differ between those who do and do not participate in EI. It would be of interest to conduct longitudinal studies of parents with low GA infants with VLBW, beginning with infants who are in the neonatal intensive care unit and continuing to the decisions to enroll. (b) Parenting belief-behavior connection continues to be a dilemma in terms of explicating the role in parenting and child outcome (Hirsjärvi & Perälä-Littunen, 2001). Because we did not directly observe parenting behavior, but did so via parent report, we commented on studying actual behavior in the discussion and future studies should explore this connection further. (c) There is a decline between rates of referral from the neonatal intensive care discharge and rates of parental participation, which may occur months later. This period remains unexplored and may be a logical target area for future study and intervention development.

This research builds evidence about how parents negotiate challenges through very early stages of their child's life and has implications of improving outcomes throughout the lifespan. Early assessment of factors that influence participation in EI may identify families that need more support early on in the first few months of the infant's life.

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ORCID iDs

Elizabeth A. Koldoff https://orcid.org/0000-0001-6465-8862
Barbara J. Holtzclaw https://orcid.org/0000-0001-6231-3342

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