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Original Article

The Prevalence of Developmental Disabilities among Children Who Received Home Cares in the Neonatal Period Despite Being High-Risk

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Abstract

Background and aims: High-risk neonates (HRNs) included neonates who were born with a weight of less than 1500 g at birth and/or gestational age between 24 and 37 weeks and needed longer intensive medical care. This study aimed to evaluate the prevalence of developmental disabilities among 5-year-old children that were HRNs in the neonatal period.

Methods: In a historical cohort study, 120 five-year-old children were included and divided into two groups of 60 eligible children in the exposed and control groups. They were born as HRNs in 2016 and admitted to the neonatal intensive care units (NICUs). After stabilization of their general condition, the infants in the exposed group were discharged and received home care (HC) services, but the control group received long-time care in NICU and did not receive HC services. They were evaluated in terms of developmental domains including vision, hearing, fine motor skills, gross motor skills, communication, problem-solving, and personal and social affairs. The developmental screening was done using the Ages and Stages questionnaire (ASQ).

Results: A total of 61 (50.83%) children were classified as suspected cases of developmental disabilities. There was no significant difference between the exposed and control children in the total frequency of developmental disability ($P=0.1$). A significant difference was seen only in the problem-solving domain between the exposed and control groups ($P=0.043$).

Conclusion: There were no significant statistical differences in most dimensions of developmental disabilities (except for the problem-solving domain) between the exposed and control children.

Keywords: Child development deviations, Child development disorders, High risk, Home care services, Prematurity

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Introduction

Low birth weight and premature birth are among the leading causes of death.[1] Additionally, premature birth is the main cause of neurodevelopmental impairment. The prevalence of neurobehavioral developmental disorders in premature infants was about 25%-50%, while in normal infants at the same age was reported to be 7%. Major differences in academic achievement and executive performance have been observed in preterm or very low birth weight children compared to normal birth weight children, especially in reading, math, and spelling.[2]

In addition to low birth weight, children up to 5 years old who required resuscitation, antibiotics for infection, and/or prolonged hospitalization after birth had lower development scores.[3]

The most important reason for assessing the development of children is the early detection of mental, motor, visual, and auditory disorders, which may be treated promptly in case of medical intervention. Otherwise, they can cause serious neurological complications and disorders. High-risk neonates (HRNs) should be recognized as soon as possible to prevent complications and death. HRNs included neonates who were born with a weight of less than 1500 g at birth and/or gestational age between 24 and 37 weeks and no longer needed intensive medical care.

A comprehensive and systematic approach is needed to assess the severity and impact of the disorder on the child's daily functioning, and planning for early interventions and special education programs for these children is of particular importance. For this purpose, screening should be done for the early detection of developmental disorders in infants.[4]

Developmental screening in infants should be performed in all domains such as language, motor, cognitive, self-regulatory, and social-emotional abilities. Developmental-behavioral problems are dynamic and require constant assessment. Evaluation of developmental-behavioral issues in primary care should be performed at all visits.[5]

According to the literature, home care (HC) after childbirth by a trained nurse is the best way to meet the educational and supportive needs of families. For parents who have just had a child, providing HC, in addition to

being more effective help, reduces maternal stress. HC also helps to identify premature neonates' problems and provides comprehensive support to neonates and better treatment.[6]

The Neonatal Health Administration of the Iranian Ministry of Health prepared a home care service package for HRNs aiming to provide adequate access to basic health care and implemented it as a pilot study in Isfahan, Iran, in March 2016. The HC package was delivered by experienced neonatal nurses following the discharge of HRNs in the early weeks after birth. The nurses who had good experiences in health care in the neonatal intensive care unit (NICU) and had the approval to provide HC services for HRNs from the Deputy of Clinical Affairs of Isfahan University of Medical Sciences (MUI) were eligible to employed.[7]

We followed all 129 HRNs who received HC in the neonatal period in this project up to one year and found that only one HRN died due to multiple anomalies.[8] As mentioned earlier, the HRNs were reported to have a higher morbidity rate compared to normal neonates.[2] However, the HRNs in the present study underwent the HC instead of the NICU cares as a pilot project. It was necessary to assess morbidity among children who received HC in the neonatal period as HRNs. This study was conducted to compare the outcomes between two groups of 5-year-old children who were born as HRNs. One group received HC instead of NICU care, while the other group received long-term hospitalization in the NICU but did not receive HC in the neonatal period.

Materials and Methods

Study Design and Subjects

This is a retrospective (historical) cohort study that was carried out from April 2016 to September 2021. The exposed (intervention) group consisted of 60 eligible 5-year-old children who were born as HRNs in 2016 in one of the 5 main public and charity hospitals that delivered the majority of labor services to pregnant women in Isfahan (Amin, Issa Ibn Maryam, Al-Zahra, Shahid Beheshti, and Asgarieh) and have been admitted to the NICU in their neonatal period in 2016 due to high-risk condition. After stabilization of their general condition, they were discharged with the consent of their parents and received HC services in neonatal periods from well-trained nurses.[9] The control group included similar 60 eligible 5-year-old children who were born as HRNs in 2016 in one of the 5 selected hospitals in Isfahan. They were hospitalized and received long-term services in the NICU in the neonatal period but did not receive HC.

The sampling was done using a convenience sampling method. In this study, 5-year-old children who were born as HRNs in 2016 in one of the 5 selected hospitals were included in the study. Children who grew up with someone other than their mothers, children whose parent's telephone number was not available, and children whose mothers were not cooperative in the telephone interview were excluded from the study.

According to the basic health care package that was launched as HC for HRNs in Isfahan in 2016, the HC had been delivered the day after the discharge of HRNs from the NICU in continuity with the NICU services for 4 weeks after birth. The HC service was delivered in coordination with the neonatologists' orders and according to mothers' consent. Other HC services were provided every week in the neonatal period. More HC services were delivered based on the parents' demand. Counseling sessions lasted an average of 60 minutes and were offered to families free of charge. HC package focused more on family training in meeting neonatal essential health needs and included training the neonates' families, helping them with breastfeeding even gavage via nasogastric tube, apnea monitoring, assisting them with the nursing of HRNs such as kangaroo mother care, evaluating neonates for signs and symptoms that require any urgent intervention, and referring them to a physician promptly if necessary.[9]

Access to the files of HRNs born in 2016 was granted in coordination with the experts of the Family Health and Population Department of the provincial health center and the authorized experts in the selected hospitals in Isfahan. The home or cell phone numbers of the parents were obtained, and they were contacted from April to September 2021. First, the researcher introduced and assured the children's parents of the confidentiality of their information. During the telephone interview, the ASQ questions were asked just when they announced their readiness.[10] The questions were asked and the data were entered into checklists for each child.

Data Collection

Data were collected using the Persian version of the Ages and Stages Questionnaire (ASQ). ASQ is used to measure the development of children at the age of 60 months. The children's development criteria included indicators in seven dimensions, including vision, hearing, fine motor skill, gross motor skill, communication, problem-solving, and personal and social domains that were evaluated using the ASQ in both the exposed and control groups.[11]

Each questionnaire contains 30 questions that are listed in simple language about children's development and the questions in each domain are arranged in increasing order of difficulty from easier activities to more difficult activities.[11] A study conducted in 2020 in Singapore showed that ASQ is a useful and valid screening tool.[5]

Using Cronbach's alpha, the reliability of the ASQ in Iranian children ranged from 0.76 to 0.86 and its inter-rater reliability was 0.93. The validity of this screening tool was satisfactory.[12]

Data Analysis

According to the national guidelines for screening the development of children, the child's condition can be classified into the following three categories (based on the age of the child): group 1: ≤ -1 SD, group 2: -1 to -2 SD,

and group 3: ≤ -2 SD below the mean.

The parents of the children whose ASQ scores were -1 to -2 SD below the mean were taught exercises to improve the growth and learning of children according to the age of the child, and after two weeks, their children were evaluated again. After re-evaluation, the children with the ASQ score of -1 ≤ SD ≥ -2 and ≤ -2 SDs below the mean in the first assessment session were considered as suspected developmental disorder cases who needed to be referred to a specialist for additional examinations.[12]

The data were analyzed using SPSS version 24.0 (IBM SPSS Statistics for Windows). Descriptive statistics including frequency and relative frequency distribution tables were used to describe the data. The normal distribution of quantitative variables in each group was confirmed using the Kolmogorov–Smirnov test. For analyzing the data, the independent *t* test and the chi-square were used. The $\alpha < 0.05$ was considered significant.

Results

A total of 120 mothers were interviewed, 60 in the exposed and 60 in the control group. As shown in Table 1, there were no significant differences in the demographic characteristics of children (e.g., age, gender, etc) in the exposed and control groups except for the parent's place of residence. None of the mothers in either group had any past family history of congenital developmental disabilities. All children in both groups were normal in terms of vision, hearing, and comprehensive abilities. In terms of speech, one child had speech disorder in the control group, while all children in the exposed group were normal in terms of speech. There was no statistically significant difference between the two groups in terms of speech ($P = 0.315$).

One child in the control group had difficulty walking. However, all children in the exposed group were normal in terms of the ability to walk. There was no statistically significant difference between the two groups in terms of the ability to walk ($P = 0.315$).

In the evaluation of 5 domains based on ASQ, a total of 61 (50.83%) children had a score greater than 1 SD below the mean, who were considered suspected cases of developmental disabilities. Out of these 61 cases, 35 (58.3%) cases belonged to the exposed group and 26 (43.3%) cases belonged to the control group. There was no significant difference between the two groups of children who received or did not receive HC in the neonatal period in the total prevalence of developmental disability (chi-square = 2.7, $P = 0.1$).

The most frequent developmental disabilities (greater than 1 SD below the mean) were observed in the domains of fine movements and problem-solving, with frequencies of 26 (21.7%) and 23 (19.17%), respectively. However, the results of the chi-square test (Fisher's exact test) revealed a statistically significant difference only in the problem-solving domain between the exposed and control groups ($P = 0.043$) (Table 2).

The results of the Chi-square test revealed no statistically significant relationship between developmental disabilities and the gender of children ($P > 0.05$). In addition, there was no significant relationship between developmental disabilities and the place of residence of children's families ($P > 0.05$).

Discussion

In this study, a total of 61 (50.83%) five-year-old children that were born as HRNs had developmental disabilities. Similar to our finding, the prevalence of developmental disabilities among infants at 24 months of age in South

Table 1. Demographic Characteristics of Children Who Were Assessed in Terms of Developmental Domains

Characteristics	Exposed to Home Care During the Neonatal Period		Total	*P* Value
	Yes	No		
Age (mon), Mean ± SD	62.78 ± 1.47	62.80 ± 1.52		0.951[a]
Gender				
Male	32	22	54	0.067[b]
Female	28	38	66	
Place of residence				
Urban areas	56	28	84	<0.001[b]
Rural areas	4	32	36	

[a] Independent *t* test; [b] Chi-square test.

Table 2. The Frequency Distribution of the Scores of Developmental Domains in the 5-Year-Old Children Who Received Home Care in the Neonatal Period Compared to Children Who Did Not Receive it

Developmental Domains	The Severity of Developmental Disorders	History of Receiving Home Care		*P* Value
		Yes No. (%)	No No. (%)	
Communication skills	≤ -2SD	0	1 (1.67)	0.413[a]
	-1 ≤ SD ≥ -2	0	0	
	≥ -1SD	1 (1.67)	0	
	Normal	59 (98.33)	59 (98.33)	
Gross motor skills	≤ -2SD	0	1 (1.67)	0.445[a]
	-1 ≤ SD ≥ -2	2 (3.33)	3 (5)	
	≥ -1SD	2 (3.33)	1 (1.67)	
	Normal	56 (93.33)	55 (91.7)	
Fine motor skills	≤ -2SD	6 (10)	8 (13.33)	0.661[a]
	-1 ≤ SD ≥ -2	8 (13.33)	4 (6.67)	
	≥ -1 SD	37 (61.67)	28 (46.67)	
	Normal	9 (15)	20 (33.33)	
Problem-solving skills	≤ -2 SD	1 (1.67)	3 (5)	0.035[b]
	-1 ≤ SD ≥ -2	14 (23.33)	5 (8.3)	
	≥ -1SD	31 (51.67)	27 (45)	
	Normal	14 (23.33)	25 (41.7)	
Personal and social domains	≤ -2 SD	4 (6.67)	1 (1.67)	0.057[a]
	-1 ≤ SD ≥ -2	0	0	
	≥ -1 SD	0	0	
	Normal	56 (93.33)	59 (98.33)	

[a] Chi-square test; [b] Fisher's exact test.

Africa was 55.3% in more than one domain.[13] According to a systematic review and meta-analysis study, the prevalence of developmental disabilities in Iran was reported to be 7%–22.4% in 2016.[14] In a national study on developmental disabilities in children aged 3-17 years in the United State of America, an increasing trend of developmental disabilities was observed from 2009 to 2017 that reached 17.8%.[15] The prevalence of developmental disabilities in our study was higher compared to the above-mentioned studies. It is necessary to emphasize that our study population was children that were born as HRN (birth weight below 1500 g or gestational age less than 34 weeks). According to previous studies, developmental disabilities are more common among children born prematurely.[15,16] However, these findings should be evaluated in future studies with larger sample sizes. The second reason for the higher frequency of developmental disabilities among children in this study can be the data collection method in this study. In the usual child developmental screening pattern, the checklist is delivered to the mothers of the children and they are asked to complete the checklist at home themselves. Then, they are asked to return it to their health care provider (at the health center) in the following days to record in their electronic health files. However, in this study, for completing the ASQ checklist, data were collected in several sessions through telephone interviews by a single researcher who was blinded to the allocation of children to each group.

According to the findings of this study, among the five domains of children's developmental status, the most frequent developmental disabilities (-1 SD) were observed in fine movements and problem-solving, with frequencies of 26 (21.7%) and 23 (19.17%), respectively. Fine movements and problem-solving were the two most frequent developmental disabilities that were reported in a study conducted by Yaghini et al.[17] Similar to these findings, in a study conducted in Brazil on 3200 children aged 0-72 months, the lowest scores in assessing the developmental status were reported in the domains of fine movements and problem-solving.[3]

Based on the systematic review in 2017, kangaroo mother care reduced the risk of mortality in low birth weight infants significantly. However, there were no significant differences between kangaroo mother care infants and controls in psychomotor development domains.[18] Peyghambardoust and Fadaei conducted a study to investigate the effect of HC on the developmental indicators of low-birth-weight infants during three months. Based on the results, there was no statistically significant difference in the mean scores of communication, large movements, fine movements, problem-solving, and personal-social dimensions, as well as the overall score of ASQ between infants who received HC and those who did not receive it.[19] In the present study, there was no statistically significant difference between the two groups of children who received or did not receive HC in the neonatal period despite their high-risk conditions except for the problem-solving domain.

There was no statistically significant difference in developmental disabilities between the children in this study in terms of gender. According to the findings of the national study done in the United State of America, developmental disabilities were more frequent among boys than girls (21.55% vs. 12.11%).[15] This finding is in contrast with our result in which there was no difference between boys and girls in terms of developmental disabilities. It seems that it is necessary to evaluate these findings in future studies with larger sample sizes.

However, in terms of residence, the children participating in this study, especially the children who had received HC in the neonatal period, lived in urban areas of Isfahan. On the other hand, HRNs living in rural areas were not suitable candidates for HC due to difficulties in delivering HC services by nurses, and fewer children entered the HC receiving group.

Study Limitation

The checklist used to collect data was based solely on the ASQ III checklist. Unfortunately, we did not collect information on the literacy level and/or occupation of the children's parents. Therefore, we did not analyze the difference between the two groups that received HC or did not receive HC in the literacy or occupation of the children's parents.

Conclusion

The results of this study indicate that developmental disorders are more frequent in children with a history of birth as HRNs. On the other hand, no statistically significant difference was found in the prevalence of developmental disorders in children who received HC services instead of long-term hospitalization in the NICUs in the neonatal period despite being HRN (except for the problem-solving domain). Therefore, it seems that HC even for HRNs with stable conditions can be a good alternative to expensive services such as hospitalization in the NICUs.

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Competing Interests

The authors declare that they have no conflict of interest associated with the material presented in this paper.

Ethical Approval

The study was approved by the Ethics Committee of Isfahan University of Medical Sciences (IR.MUI.MED.REC.1399.320).

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