

## Clinical Outcomes of High-Risk Infant Follow-Up Program in a Tertiary Care Centre

### Abstract

**Background:** High-risk infant follow-up (HRIF) program is necessary for early detection, timely intervention, and promotion of health outcomes in vulnerable infants, ethically. The present study was carried out to assess the clinical outcomes of the HRIF Program in Alzahra hospital as a tertiary care centre, in Iran. **Materials and Methods:** In this cohort study, 5840 neonates were born at Alzahra hospital, from June 1, 2011 to 30<sup>th</sup> February 2012. Among those who were admitted to neonatal intensive care unit (NICU), 253 infants were recruited by census according to HRIs criteria. After doing necessary measurements and family education, information was recorded in HRI health certificate and then entered in the access database for analysis. **Results:** From 253 eligible HRIs registered, 241 (95%) infants attended the follow-up clinic after discharge. A total of 180 cases were recalled for further visits, 110 of which attended the clinic. Anthropometric indices had an increasing trend in the first 6 months of life. There was no significant relation between ages and stages questionnaire (ASQ) results and infant birth weight, height, and head circumference. The ratios of intraventricular hemorrhage (IVH) and retinopathy of prematurity (ROP) were 8.7% and 3.1%, respectively. The incidence of congenital hypothyroidism was 2:341 in HRIs. **Conclusions:** Although some outcomes, such as ROP, improved in our study compared to similar studies, the findings indicate an impairment of the current follow-up processes and highlight the necessity to modify the current HRIF program. Ethically, we insist on integrating HRIF program in child health services to promote early childhood development.

**Keywords:** Ethics, follow-up, infant development, Iran, high risk, tertiary care center

### Introduction

Improvement in neonatal survival is followed by an escalation in morbidity and developmental disorders among graduates of NICUs, due to the biological vulnerability of these infants.<sup>[1]</sup> After clinical complications such as sepsis, chronic lung disease (CLD) and intraventricular hemorrhage (IVH), developmental and behavioural disorders including motor coordination disorders, behaviour problems, attention deficit hyperactivity disorder (ADHD) and reduced educational achievement are the most common problems in high-risk infant (HRIs).<sup>[2]</sup> Delay in diagnosis and treatment results in several complications that threaten the early childhood development as one of the social determinants of health.<sup>[3,4]</sup> Developmental screening must be done in cognitive, psychomotor, emotional, social, and communication fields, and also for hearing, speech, and visual disorders.

A developmental screening utilizes systematic approach by trained personnel and interpretation of parent reports.<sup>[2]</sup>

Study of short- and long-term outcomes at 2-, 5-, and 8-year-old for neonates at borderline viability has shown that local figures for mortality and morbidity remained high at the limits of viability.<sup>[5]</sup> Therefore, high-risk infant follow-up (HRIF) program is necessary for early detection and timely intervention for probable impairments, ethically. Also, implementation of this program helps to evaluate the quality of care in NICU/tertiary care centre. Although substantial resources are required for these interventions, HRIF program links pre- and post-NICU discharge care to assure that high-risk infant reach optimal well-being and developing levels.<sup>[6]</sup>

Despite the extension of NICUs in Iran and increased survival of preterm infants, there was no follow-up program in our health system until 2012. Heidarzadeh

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et al. (2013) created an action model of HRIF program based on California guidelines. In this national model, HRIs are identified and labelled after admittance in NICU and care begins as soon as possible according to national HRI service package by the follow-up team. The members of the follow-up team included coordinator, neonatologist, discharge nurse, clinic nurse, ophthalmologist, audiologist, and neurodevelopment specialist.<sup>[7]</sup>

The coordinator was a neonatologist who played a key role in the scientific and executive management of follow-up care program. The discharge nurse was an experienced NICU nurse who determined and registered the HRIs, trained parents and prepared them for taking care of their babies, and informed them about the necessity to refer to follow-up clinic according to the schedule, at the time of discharge from NICU. The clinic nurse was a trained nurse who coordinated with follow-up team and parents during follow-up visits. She was responsible for recording HRIs' health certificate booklet, data entering, coordinating with other subspecialists in need of a referral, training parents about how to complete ages and stages questionnaire (ASQ) and family recalling. The follow-up visits included required assessments, screening tests, diagnosis, treatment, and referral if needed, and also parents' education according to timetable based on corrected gestational age. Different aspects and problems that an HRI may encounter were being recorded in the HRI certificate booklet in order to unify the visits performed by physicians and also parents notification.

Regarding the importance of caregiving for HRIs and its feedback to improve the quality of care, HRI surveillance system has been innovated in 2015.<sup>[8]</sup> Thus, assessment and evaluation of the long-term outcomes are possible. Assessment of HRIF outcomes requires counselling of parents, health planning and providing education. Moreover, evaluation of those services helps us to facilitate understanding of the short- and long-term effects of preterm birth, especially in the developmental domain. After creating an action model for HRIF (2012–2013), this study was carried out with the purpose of assessing the short-term clinical outcomes of the HRIF program implementation in Alzahra Hospital as a tertiary care centre of the Tabriz University of Medical Sciences, Iran.

## Materials and Methods

In this cohort study, 5840 neonates were born from June 1, 2011 to 30<sup>th</sup> February 2012, in Alzahra Hospital of the Tabriz University of Medical Sciences and 1238 (21.2%) of them were admitted to NICU. Among those admitted to NICU, 253 infants were recruited by census and labelled as HRIs according to the following HRI criteria: birth weight less than 1500 grams or gestational age <32 weeks or birth weight more than 1500 grams or gestational age ≥32 weeks with one of the following conditions: intrauterine growth retardation, birth asphyxia, severe instability such as

prolonged and resistant hypoxia/hypoglycemia/hypotension, resistant apnea required medical treatment, IVH (grade 2 or higher), and fetal distress syndrome.

Infants who were transferred to other hospitals or discharged with palliative care were excluded from this study. After transferring 42 infants to other hospitals for special interventions such as surgery, and death of 46 infants, 253 HRIs remained [Figure 1]. After registration of HRIs admitted to the NICU ward, necessary care and performance of the required tests such as screening for hypothyroidism or retinopathy of prematurity (ROP) and other necessary interventions, their parents were notified about the importance of HRIF program and the timetable of attending the follow-up clinic by the discharge nurse. At the end of hospitalization period, the discharge nurse trained the parents for attending the follow-up clinic. According to the clinical guideline, the first follow-up visit was due in 24 to 48 hours after discharge and the next calling were based on both the timetable and birth weight. The list of discharged HRIs has been presented to the clinic nurse after discharge. If they did not report back on time, the clinic nurse reminded them. Follow-up visits were performed by neonatologists and information were recorded in HRIs' health certificate and then, entered into the access database for analysis and interpretation.

ASQ has been used for developmental screening at the second and fourth month of the birth. Adaptation and standardization of this test in Iran were performed under the supervision of Ministry of Health and Medical Education, Office of Population and Family Health, United Nations Children's Fund, International Council for the Education

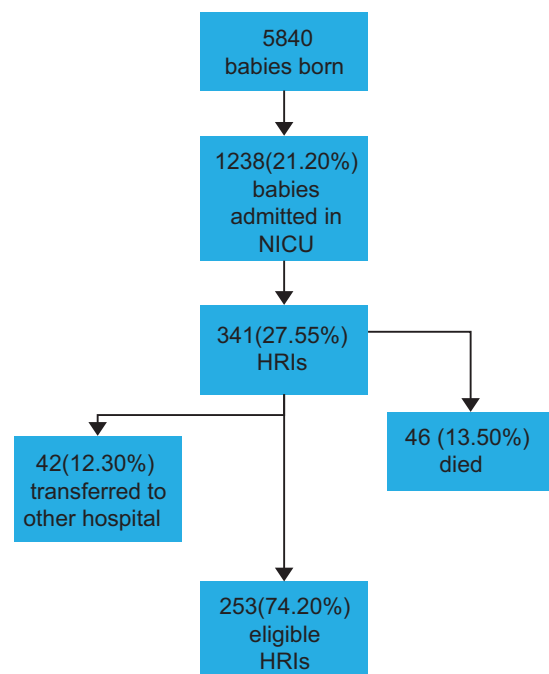


Figure 1: The number of eligible high-risk infants

of Exceptional Children, and Institute for Exceptional Children in the years 2002 to 2007. The validity and reliability of the test have been established as 0.84 and 0.94, respectively, and its reported ability to determine developmental disorders is more than 96%.<sup>[9]</sup>

At the time of discharge, parents were taught to complete ASQ at the second month of the birth. Then, ASQs were returned and interpreted by the physician; HRIs who didn't meet the cutoff point score in any one of the fields were referred to the development specialist for an extended developmental test, Griffiths test.<sup>[9,10]</sup>

Examination for IVH, screening for congenital hypothyroidism and ROP were performed during the first hospitalization, but subsequent assessments and also examination and assessment for ADHD and autism were performed during follow-up visits.

### Ethical considerations

This research was ordered by Ministry of Health and Medical Education, Deputy of Public Health, Neonatal Health Office, and was approved by the Research Deputy of Tabriz University of Medical Sciences (the proposal ID: 98-89, the ethics committie ID: 8919/4/5). Parents' informed consent was obtained for participation in the HRIF program.

### Results

More of the HRIs born through cesarian section (73.5%), male (70%) with gestational age <32 weeks (80.5%) and birth weight <1500 grams (61%). Table 1 shows the frequency of delivery mode, sex, gestational age, and birth weight of the HRIs.

From 253 eligible HRIs registered, 241 (95%) infants were attained in the follow-up clinic after discharge from NICU. We called back 180 cases for further visits, 110 (61%) of which returned to the clinic. A total of 80.5% of them had gestational age <32 weeks and 61% weighed less than 1500 grams.

Anthropometric indices including head circumference, height and weight, the trend of their means follow-up visits were high during first 6 months of life [Table 2].

ASQ test was performed at 2 and 4 months of corrected age. A total of 160 out of 175 tested infants passed the test and 15 of them failed (8.57%). There was no significant relation between ASQ results and infant birth weight, height, and head circumference. The ratios of IVH and ROP were 8.7% and 3.1%, respectively. The incidence of congenital hypothyroidism was 2:341 in HRIs [Table 3].

### Discussion

We piloted HRIF program in a tertiary centre and assessed short-term clinical outcomes after designing the program

**Table 1: The frequency of delivery mode, sex, gestational age, and birth weight of the high-risk infants (HRIs)**

Variable	Number (%)
Delivery Mode	
Caesarean	177 (73.5)
Vaginal	62 (25.7)
Forceps	2 (0.8)
Sex	
Male	170 (70)
Female	71 (30)
Gestational age (weeks)	
<28 week	70 (29)
28-32 week	124 (51.5)
32-36 week	40 (16.6)
>36 week	7 (2.9)
Birth weight (g)	
<1000	109 (45)
1000-1500	38 (15.8)
1500-2500	80 (33)
≥2500	14 (6.2)

**Table 2: The mean (SD) of anthropometric indices in high-risk infants (HRIs)**

Corrected gestational age	Mean (SD)		
	Weight (gm)	Height (cm)	Head circumference (cm)
2 weeks	1797 (267)	42.4 (2.5)	30.6 (1.5)
1 month	2122 (429.5)	44.4 (3.1)	31.5 (1.6)
2 months	2911 (873)	47.8 (4.2)	33.5 (2.3)
3 months	3979 (1683)	52.9 (9.1)	35.7 (2.8)
4 months	4428 (1037)	54.8 (4.7)	37.2 (2.0)
5 months	5512 (695)	59.2 (3.5)	39.0 (2.5)
6 months	6435 (1250)	63.3 (4.5)	41.3 (2.2)

**Table 3: The frequency of the complications in high-risk infants (HRIs) based on gestational age**

Clinical outcome	Num. of examined infants	Num. of complicated infants				Total n (%)
		<28	28-32	32-36	>37	
IVH	241	13	7	1	0	21 (8.7)
ROP	194	5	1	0	0	6 (3.1)
Hypothyroidism	341	0	0	0	2	2 (8.3)
ADHD	22	0	3	0	0	3 (1.24)
Autism	16	0	0	0	0	0

and defining the HRIs criteria. As mentioned, we recalled 180 cases for further visits, 110 (61%) of whom were followed up. This result can be due to inadequate access to the rural families. According to Eskandari *et al.* (2013), health care outcomes are related to the cultural and social context of communities, and structure of the health system.

[11] This finding represents an impairment of the current

health care process and necessity of modifying the existing HRIF program.

Increasing trends of anthropometric indices including head circumference, height, and weight during follow-up visits at 6 months of life indicated the effectiveness of visits on HRIs growth. Heidarzadeh *et al.* (2015) had similar results.<sup>[12]</sup> We did not find any significant relation between ASQ test results and infant birth weight, height, and head circumference. Glasson and Petterson did not also report any correlation between anthropometric indices and cognitive developmental disorders.<sup>[13]</sup> Amir-Ali-Akbari, *et al.* (2010) found no correlation between height and head circumference at birth and developmental delay by ASQ test among children aged 4–20 months. However, they found that the birth weight of children with developmental delay was four times lower than that of children with normal development.<sup>[14]</sup> This difference can be due to the different target group and also the time of taking the ASQ test in the mentioned study.

IVH is one of the major complications in premature infants, and an appropriate predictor of neuro-developmental outcomes in very low birth weight neonates.<sup>[15,16]</sup> The ratio of IVH in the present study was 8.7%. IVH grades 1, 2, 3, and 4 were found in 38.3%, 33.1%, 14.3%, and 14.3% of cases, respectively. Jodeiry *et al.* (2012) also studied 64 cases with IVH of very preterm infants in Alzahra hospital. Mean of gestational age was 28.782.08. Sixty-four cases (36.6%) in their study had IVH. IVH grades 0, 1, 2, 3, and 4 were found in 64.43%, 20.57%, 3.43%, 10.29%, and 2.29% of cases, respectively.<sup>[17]</sup> Saima *et al.* showed that 13% of preterm infants (13 from 100 cases) developed IVH: 30.76% grade 1, 7.7% grade 2, 46.2% grade 3, and 15.4% grade 4 IVH.<sup>[18]</sup> Of course, greater ratio of IVH in their study may be due to the smaller sample size.

The ratio of ROP in the present study was 3.1% in HRIs. The most important risk factor for ROP is prematurity. Preventive measurements including screening are the best treatment if the disease occurs and close follow-up is necessary. In the present study, with increasing gestational age ROP declined, as expected Fayyazi *et al.* (2009) reported 7.27% ROP in the hospitalized infants with gestational age <32 weeks in Alzahra hospital.<sup>[19]</sup> Bayat-Mokhtari *et al.* (2010) showed that of 199 preterm infants, ROP requiring laser therapy was detected in 19 (9.5%) cases and in 65 (32.6%) cases ROP regressed spontaneously, at tertiary hospitals of Shiraz University, Iran.<sup>[20]</sup> Through a cohort study, Babaei *et al.* (2012) reported 13% ROP in the hospitalized infants with birth weight ≤1500 grams in Kermanshah city, Iran.<sup>[21]</sup> Feghhi *et al.* (2012) reported 32% ROP in the hospitalized infants with birth weight ≤2000 grams or <32 weeks, in the south-western region of Iran.<sup>[22]</sup> Akçakaya *et al.* (2011) reported 34% ROP in the hospitalized infants with gestational age ≤33 weeks in Istanbul.<sup>[23]</sup> ROP is emerging

as the major cause of blindness in middle-income countries. High rates of premature birth and increasing survival rate of preterm infants, often with suboptimal care, have resulted in a third epidemic of ROP. Hence, timely screening and treatment are urgently needed to control the third epidemic.<sup>[24]</sup>

In our study, incidence of congenital hypothyroidism was 2:341. Baf *et al.* (2016) reported this incidence rate in the province of Razavi Khorasan, Iran to be 2.13:1000.<sup>[25]</sup> Dilli *et al.* reported the overall incidence rate of congenital hypothyroidism (2008–2010), 1:650 in Turkey.<sup>[26]</sup> Although the incidence of congenital hypothyroidism in Iran is high, but the higher incidence in our study is related to target group; HRIs.

Our study limitations were assessing the outcomes in a 6 months period and incomplete data entry that can affect the findings. Another problem was the budget; for continuing this system we trained and engaged two nurses: one discharge nurse and the other clinic nurse but these fields have not been defined in our health system. Our suggestion for further study is an evaluation of the long-term clinical and developmental outcomes in HRIs through a cohort study.

## Conclusion

Although some outcomes, such as ROP improved in our study compared with similar studies, the findings indicate on impairment of the current follow-up processes and necessity of modifying the HRIF program. Long-term evaluation through surveillance system can help us to improve clinical and developmental outcomes among HRIs for better health and well-being. It may also help us to understand the outcomes of preterm birth, especially in the developmental domain. Ethically, we suggest integrating the HRIF program to child health services in the whole country, in order to promote early childhood development as a powerful equalizer and social determinant of health.

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## Conflicts of interest

The authors declare that there is no conflict of interest.

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