

Review Article

Neonatal follow-up program: Where do we stand?

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ABSTRACT

Neonatal follow-up program (NFP) is becoming the corner stone of standard, high quality care provided to newborns at risk of future neurodevelopmental delay. Most of the recognized neonatal intensive care units in the developed countries are adopting NFP as part of their mandatory care for the best long term outcome of high risk infants, especially very low birth weight (VLBW) infants. Unfortunately, in the developing and in underdeveloped countries, such early detection and intervention programs are rarely existing, mainly because of the lack of awareness of and exposure to such programs in spite of the increasing numbers of surviving sick newborns due to advancement in neonatal care in these countries. This is a review article to explore the Neonatal follow-up programs looking at historical development, benefits and aims, and standard requirements for successful program development that can be adopted in our countries. In conclusion, proper Neonatal follow-up programs are needed to improve neonatal outcome. Therefore all professionals working in the field of neonatal care

in developing countries should cooperate to create such programs for early detection and hence early intervention for any adverse long term outcome in high-risk newborn infants

Key words: Neonatal follow-up program (NFP), high risk infants, long term developmental outcome, NICU.

INTRODUCTION

With the advancement in neonatal intensive care units and introduction of new technologies in resuscitating and ventilating tiny newborns, the numbers of surviving extremely low birth weight infants is increasing and the potential of having children with long term disabilities is on the rise. A method of early detection and hence early intervention is mandatory in order to prevent or minimize future handicaps in this group of infants. Researchers over decades addressed this problem and found that the best solution is based on the development of proper neonatal follow-up program which should be an integral extension

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of every neonatal intensive care unit. Specialized care must be made available for problems of growth, development, and chronic disease and is best provided within the setting of neonatal follow-up program [1].

Historical background

During the past century, the care of preterm infants evolved from the Tarnier's agricultural incubators adapted for use in human infants to the well-described incubator baby displays at World's Fairs in Coney Island, New York [2] to the survival of occasional preterm babies from the display incubators to the first 'preemie baby units' in the 1920s and 1930s.

But even during those early years, while neonatology was developing as a specialty and neonatal intensive care practices were being refined, there was attention to the long-term outcomes of the small 'preemies'. An intriguing and important early outcome report by Hess [3] on babies born in the 1930s was followed by carefully conducted and reported follow-up studies by Lubchenco et al [4] and Drillien [5] describing infants cared for in the 1940s and 1950s. Their reports of surviving preterm babies delivered the tragic news that up to two-thirds were disabled. These early follow-up studies laid some of the groundwork for neonatal intensive care and neonatal follow-up as they exist today

Several Canadian investigators contributed important findings in outcome studies of groups of very low birth weight infants or term infants who experienced neonatal complications between 1960 and 1990. An early example was a report on the fate of the ex-premature by Grewar et al [6] from Winnipeg, Manitoba. Buck et al [7], in a classic report, described the 12-month outcomes of children of premature birth weight from the Ontario Perinatal Mortality Study, stressing

important methodological issues, such as the inclusion of comparison or control subjects in neonatal outcome studies.

Additional reports from Canada over the past two decades have continued to provide methodological insights into the design of neonatal outcome studies, including the use of geographically based populations [8, 9] and the introduction of more appropriate testing approaches [10].

Small sample sizes, heterogeneity of cohorts and methodology, diversity of perinatal intensive care practices, and the high cost of randomized controlled trials (RCTs) and follow-up care have all contributed to the lack of rigorous data on the sequelae of preterm delivery and the therapies used to improve the long-term outcome of high risk infants [11].

These findings led to the recognition of the need to improve standardization and comparability of methodology and data collection within and among centers and networks as the first step toward research to improve the long term neurodevelopmental outcome of high-risk infants.

Currently, neonatal follow-up programs in Canada are moving toward the development of a national neonatal follow-up database in conjunction with the Canadian Neonatal Network [12]. Increasingly, multicentre, randomized controlled clinical trials have incorporated the measurement of long-term outcomes of infants, relying on the structure and procedures that already exist in Canadian neonatal follow-up programs [13, 14]. Also, reports on older children, adolescents and adults have added an important new dimension to Canadian follow-up studies.

A workshop on follow-up care of high-risk infants sponsored by the National Institute of Child Health and Development (NICHD) and the National Institute of Neurologic Diseases

and Stroke was held in Bethesda, Maryland, on June, 2002 to define optimal methods to assess the outcome of infants at high-risk.

Currently, there are no nationally representative data on high-risk infant follow-up practices in the United States [15], this study showed that the majority of neonatal follow-up programs associated with academic centers in the United States are functioning as multidisciplinary programs providing clinical care, trainee education, and facilitating outcomes research.

Review of the literature and web sites did not reveal any existing standardized NFP in the under-developed or developing countries. It is true that there are many reports about long term as well as short term outcome of high-risk infants, but these measures were assessed by multidisciplinary approach or referral system to concerned specialties. There might be programs running in some of these countries in some centers but not published in the web sites, for example, at King Khalid University Hospital in Riyadh, we established the first Neonatal Follow-up program in the country in 1999, but did not create a web site or introduced it to media (this review will include the first introduction to our program) although we had published articles about short and long term outcome based on data from NFP. [16, 17], and one case report "in press" [18].

Goals and aims of NFP

Review of the literature and various existing NFPs in developed countries agreed on the following aims and purposes of having NFP:

- early detection of any deviation from normal child development in the future and hence starting early intervention.
- family education and support.
- training of medical professionals.
- facilitating research.

Discharge planning

Discharge planning is considered by many centers as part of neonatal follow-up program. It is the first step to successful follow-up of high risk babies aiming at preparing the babies for discharge after resolving all problems that require hospitalization. The American Academy of Pediatrics (AAP) had resolved the issues of discharging babies from NICU by developing discharge planning guidelines [19] which will ensure that all newborns are discharged from NICU in good condition, parents are ready to manage the baby at home, home environment is ready to receive the new comer, all required services are easily reachable, all home support available, communication with health facilities arranged, and follow-up appointment given.

Standard NFP

There are no standardized guidelines for follow up of high risk infants even in tertiary care centers; [20] services provided depend on resources. Many centers in developed countries developed their own web-sites and made NFP brochures introducing their programs and the extent of their services to their customers.

Cases which can be included in the program are decided by the strength of available resources, and services provided. The high-risk list can be long or can be short. So each center should have its own enrollment criteria and its own guidelines as long as it fulfills the purpose of NFP.

Early detection and early intervention are the key points for successful NFP [21]. Available resources will make the difference between centers providing NFP even in the same area.

Table 1 lists services and specialties that can be offered by the Neonatal Follow-up Program.

Table 1- Services provided by Neonatal Follow-up Program.

Neonatology	Ear, nose, and throat (ENT)
Pediatric neurology	Psychology
General pediatrics	Psychiatry
Audiology	Social service
Ophthalmology	Genetics
Physiotherapy	Nursing
Occupational therapy	Pulmonology
Speech therapy and swallowing	

Where do we stand?

Neonatal follow-up program at King Khalid University Hospital (KKUH) started on December 1999 as the first program in Saudi Arabia. It is run by the neonatal intensive care unit (NICU) and designed based on Winnipeg, Manitoba model. We adopted discharge planning system based on American Academy of Pediatrics (AAP), 2005 guidelines. Antenatal counseling is done for at high-risk pregnant mothers if feasible, and upon arrival to NICU our discharge planning system is activated. Booklets in Arabic language introducing the unit and all expected instruments and interventions, along with instructions

on how to express breast milk is given to parents after their first meeting with the admitting consultant who will explained the baby's condition and outline the management plan and expected outcome.

Our aims are: to provide an early detection- early intervention program for infants at high-risk, utilizing the NFP as an evaluation tool for NICU practices, train neonatology fellows, and facilitate research.

The team consists of a neonatology consultant, a registrar, a resident, a nurse, a physiotherapist, an occupational therapist, and a speech therapist. We only see and evaluate graduates of our own NICU. The schedule of the clinics is shown in table 2.

Table 2- Clinic schedule of Neonatal fellow up program at King Khalid university hospital, Riyadh.

Day and time	Clinic	Service provided
Every Saturday 8 Am – 12 noon	HRC	General examination and sorting To select eligible infants for testing
Every Sunday 8 Am – 12 noon	BINS	Screening for Neurodevelopment
Every other Tuesday 8 Am – 12 noon	Gesell	Evaluation for developmental Quotient (DQ)
Every other Tuesday 8 Am – 12 noon	HRC	General examination and sorting To select eligible infants for testing
Every Wednesday 8 Am – 12 noon	BINS	Screening for Neurodevelopment

BINS - Bayley infants neurodevelopmental screener, Gesell - Gesell Schedule of infants development, HRC - high risk clinic

First visit for neurodevelopmental evaluation will be at 8-9 months corrected age. The screening test used is Bayley Infants Neurodevelopmental Screener (BINS) [22], which is used until infants reach the corrected age of 24 months. Detailed developmental evaluation is done by the use of Revised Gesell Developmental schedules. We refer our patients to appropriate sub-specialties for required intervention

within the hospital. Infants who are candidates for standard developmental testing are selected according to high-risk list (Table 3). At the end of each visit, the result of the test is communicated to the care giver, then a full explanation and instructions given in order to prevent future handicap, referrals to needed specialties are made according to the defective area in the developmental test result.

Table 3- High-risk enrollment criteria for neonatal fellow up program at King Khalid university hospital, Riyadh.

	Condition	Pre-requisite
1	Birth weight 1500 grams or less	Check hearing and vision With abnormal central nervous system findings
2	Five minutes Apgar score < 4	
3	Neonatal seizures	
4	CNS Abnormalities: Hydrocephalus, abnormal CNS exam, abnormal imaging Results other than IVH, Periventricular Leukomalacia	
5	Intra-ventricular hemorrhage	Check hearing
6	Meningitis	
7	Congenital infections	
8	Congenital anomalies (Syndromes)	Check hearing
9	Persistent pulmonary hypertension	
10	Severe hypoxic event	Check hearing and vision
11	Diaphragmatic hernia	
12	Bronchopulmonary dysplasia	Check hearing
13	Hyperbilirubinemia – (indirect Bilirubin > 400 mmol/l)	
14	Intra-uterine growth retardation	
15	Doctors concern	
16	Mothers concern	

CONCLUSION

Neonatal follow-up programs are the best tools (up-to-date) available for proper neurodevelopmental evaluation and follow-up of high-risk infants who are increasing in numbers. Each neonatal intensive care unit should have its own program, or, collaborate with other big units to develop a referral program that can cover all these units. More exposure and introduction must be made to all persons working in the field of neonatology to the importance of NFP which should

be the first step of developing proper programs in the third world countries. Resources are the major obstacle in developing NFP, but this should not prevent us from proceeding according to our own available resources. Means and ways to overcome financial issues should be entertained by both professionals and policy makers. The ultimate aim is to prevent developmental delay and ensure healthy future for at risk neonates.

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