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Original Article

Creating the Action Model for High Risk Infant Follow Up Program in Iran

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Abstract

Background: Intervention in early childhood development as one of the social determinants of health, is important for reducing social gap and inequity. In spite of increasingly developing intensive neonatal care wards and decreasing neonatal mortality rate, there is no follow up program in Iran. This study was carreid out to design high risk infants follow up care program with the practical aim of creating an model action for whole country, in 2012.

Methods: This qualitative study has been done by the Neonatal Department of the Deputy of Public Health in cooperation with Pediatrics Health Research Center of Tabriz University of Medical Sciences, Iran. After study of international documents, consensus agreement about adapted program for Iran has been accomplished by focus group discussion and attended Delphi agreement technique. After compiling primary draft included evidence based guidelines and executive plan, 14 sessions including expert panels were hold to finalize the program.

Results: After finalizing the program, high risk infants follow up care service package has been designed in 3 chapters: Evidence based clinical guidelines; eighteen main clinical guidelines and thirteen subsidiaries clinical guidelines, executive plan; 6 general, 6 following up and 5 backup processes. Education program including general and especial courses for care givers and follow up team, and family education processes.

Conclusion: We designed and finalized high risk infants follow up care service package. It seems to open a way to extend it to whole country.

Keywords: High risk infants, Early childhood development, Follow up program

Introduction

Early childhood development (ECD) has a key role in health and development of further years of life, and role plays in health equity, across the life time through physical, social/emotional, and language/cognitive domains. These domains are influenced by early life circumstances and experiences that are underlying social determinants of health. Environmental stimulation, support, and nurtu-rance influence all three key domains of ECD. Further more intervention in ECD as one of the social determinants of health is important for reducing social gap and inequalities(1,2). Studies are showing that qualified family environments influence development and can be enhanced through interventional programs including improved parenting skills, nutritional supplementation and child care measurements. Although long-term foll-ow up has done only in some of these studies,

the results have been promising (3, 4). By definition, high risk infant (HRI) includes "any neonate, regardless of birth weight, size, or gestational age, who has a greater than average chance of morbidity or mortality, especially within the first 28 days of life."(5). HRIs need to some special care by physicians and nurses during hospitalization and after discharge. Thus this situation threatens the childeren's health and development as well as the high costs for the health system. By considering different disorders suffered during bedridden at hospital and also failure of performance of diffe-rent organs in these infants, they have to be assessed for these points: performance of nervous system, feeding and endocrin system disorders such as performance of thyroid gland or calcium and phosphorus homeostasis, possible anemia, hearing and visual disturbances, mental and behavioral health assessment, neurodevelopmental development, dental problems and etc.

One of the most important component of post discharge management in high risk infants is long term assessment through a follow up system. Progressing in the follow up care program for detection of high risk infants along with care taking, give a mechanism for monitoring and evaluation of the quality of care and the current methods in Neonatal Intensive Care Unit (NICU). High risk infants follow up leads to early detection and timly intervention for probable impairments and improvment of ECD.

By extending primary health care services and introducing advanced technology and programs for taking care of very premature infants , neonatal and infant mortality rate has been reduced(6). With increasing survival among graduated infants of NICUs, follow-up programs have focused their resources on long-term outcomes of the most vulnerable groups: very low birth weight and extremely low birth weight ((less than 1500 gm and less than 1000 gm, respectively) neonate infants (7). Considering to extention of NICU wards in Iran, it seems to be necessary to create a follow up program for HRIs, since the number of these infants is increasing. Therefore the pre-sent study was carreid out to design High Risk Infants Follow up Program (HRIFP) in Iran, in 2012.

Methods

This qualitative study has been done by the Neonatal Department of the Deputy of Public Health in cooperation with pediatrics health research center of Tabriz University of Medical Sciences (TUMS). The study was carried out with the purpose of designing HRIFP with the practical aim of creating an action model for whole country, in 2012. We applied international document study include current program for NICU graduated infants of California and Iowa (USA), Australia in developed countries and India in developing countries (4). Consensus agreement about adapted program for Iran has been accomplished by focus group discussion and attended Delphi agreement technique. After compiling a primary draft included evidence based guidelines and executive plan, 14 sessions were hold including expert panels to finalize the program. The participants were executive managers and academic staff of different courses including Neonatology, Endocrinology, lung, Gastroenterology, Neurology, Psychology, Neurodevelopment, and Rehabilitation and etc., and also physicians and expert staff of the governmental and private sectors. For confirmability of the study, we concidered Bracketing , member check, triangulation, Peer review (8,9). Nothing Discharge Nurse in current care taking system was accounted an importance limitation in our designed program that must be considered and traind in the standard staff context of NICU ward.

Results

After finalizing the program, HRIF service package has been designed in 3 chapters:

I. Evidence Based Clinical Guidelines; we compiled eighteen main clinical guidelines and thirteen subsidiaries clinical guidelines (Table 1)
II. Executive Plan; we defined 6 general, 6 following up, and 5 backup processes (Table 2).
III. Education program including general and especial courses for care givers and follow up team, and family education processes. We de-

fined 3 family education processes; education during hospitalization in NICU ward, education at the time of discharge, and education during follow up and after discharge. In the section of executive program, all processes including general and backup processes have considered. The structure of the processes in the mentioned program has been shown in Fig.1. The first and most processes were determining and registering HRI. After admission the neonate at NICU ward and applying the necessary diagnosis, care and treatment, one can determine if the infant is in the HRI group or not, according to the HRI defined criteria. In coordination to physician, the infant is checked according to HRI including criteria; if infant is in the HRI group then the corresponding procedure will be continued. Otherwise the infant will be considered in low risk group. In the follow up visit process; physical examination, detecting abnormal findings and planning necessary interventions, other assessments based on suggested time table and determining the next referring time is done by physician.

Table 1: Titles of evidence based clinical guidelines

	Main clinical guidelines	Subsidiary clinical guidelines
1	Growth assessments (based on corrected age for preterm neonates)	
2	Periodic Cardiac Examinations	
3	Hypertension Assessment	
4	Gastro Esophageal Reflux Disease	
5	Chronic Lung Disease (Prevention of Respiratory syncytial virus)	
6	Bronchopulmonary Dysplasia	
7	Hypothyroidism Screening	
8	Osteopenia	
9	Nutrition	Nutritional Assessment
		Anemia
		Supplementation
10	Nephrocalcinosis	
11	Tubular Impairments of Kidney	
12	Intra ventricular hemorrhage	
14	Developmental Dislocation of Hip	
15	Immunization	
16	Mental Health	Attention deficit-hyperactivity disorder
		Autism
		Behavioral disorders
		Child Abuse& Neglect
		Sleep Disorders
		Feeding Disorders
17	Dental Health	
18	Nero Developmental Assessment	Neurologic Disorders
		Developmental screening and assessment
		Hearing assessment(Automated Auditory Brain Stem Response)
		Assessment for Retinopathy of prematurity

Fig. 1: Structure of the processes in the mentioned program

Ages and Stages Questionnaire (ASQ) for the next calling is educated and delivered to the parents based on neurodevelopment groups and ages time tables. When ASQ as a screening test fails in a special field or the parents worry or the physician finds any doubtful point in his/her investigation, Griffith's test as a more specific and extended neurodevelopment test is used to investigate more closely. While coordinating with regionalization of perinatal services, it was supposed to choose a pediatrician for each city of province, with the level II center to attend a workshop, so that could be able to manage the follow up visits.

Table 2: Executive processes list

Row	Title	List	Details
1	General	Admission of neonate in NICU ward	
		Determining of the HRI	according to HRI including criteria
		Registering and Labeling the HRI	
		Education of parents	
		Supportive actions for family	Financial and Emotional support
		Pre discharge measures	
2	Follow up Processes	Recording of HRI	
		Visiting of high risk infants in follow up clinic	physical examination, diagnose and treatment of probable disorders and recommendation for next visit
		Assessment and Screening	by ASQ and other standard questionnaires
		Documentation	Health certificate notebook of HRI
		Referral actions	
		Family recall	
3	Backup Processes	Human resource	Defining follow up team, its members and their responsibilities and tasks
		Financial	Tariffs in governmental and private sectors
		Equipment and Materials	Standards of space, tools and questionnaires
		Data gathering	By Access data base
		research and training	

Access data base applied for data collection of HRI following up visits, by considering all information about these infants including perinatal care, problems during NICU admission and data of fol-

low up visits, ASQ screening test, Griffith's test and etc.

Regarding to need for documentation, a health certificate notebook was designed and printed for HRIs which contains all important information and data include past medical history, clinical findings, laboratory results, radiology reports, developmental tests and growth charts from birth up to five years old, which is hold by the parents.

Then educational plan was organized for two target groups; care givers and infants' family/parents including of holding 2-3 days workshops to train physicians, NICU staff and members of follow up team include general and professional courses.

For preparing and educating the family/parents, different educational methods include face to face, group and peer group education by applying video tapes and pamphlets used during admission, before and after discharge.

In these processes, Discharge and NICU nurses are responsible for educating the parents about current and major problems of this group of infants such as breast feeding, Kangaroo Mother Care, massage therapy and other necessary and special cares for special problems. Moreover, we compiled an educational content include current and major problems of HRI for preparing family/parents to contribution in their infants care in NICU and at home.

Discussion

We designed and finalized HRIF service package including evidence based clinical guidelines, executive program and family education plan. Our findings show need to collect and record data for looking out, and designing proper interventions and evaluation of the program. Early diagnosis and intervention in this program are the important elements in reducing the intensity of the possible various disorders and disabilities in high risk infants.

The Children's Medical Services (CMS) Branch/California Children's Services (CCS) Program is restructured the NICU/HRIF Program effective July 1, 2006. A HRIF Program Letter 01-0606 was dictated to provide guidance on the program restructure, including criteria of HRI, diagnostic services, and providers' responsibilities, reporting requirements, and procedures for billing authorized HRIF services provided to CCS HRIF eligible infants and children. According to CCS Standards for NICUs , each CCS-approved NICU shall ensure the follow up of HRIs discharged from the NICU itself or through an formal agreement for the provision of these services by another CCS-approved NICU (4). The CCS HRIF Program provides some of diagnostic services for children up to three years of age, while in the present study, HRIF Program provides for a number of both screening and diagnostic services for children up to five years old.

Similar to Children's Medical Services (CMS) Branch/California Children's Services (CCS) Program, we organized a multidisciplinary team of professionals and developed access data base HRIF Reporting System to collect data for the HRIFP. The reporting system will be able to identify quality improvement opportunities for NICU wards in the reduction of long term morbidity; allow programs to compare their activities with all sites throughout the country.

In their program, at the time of the referral for HRIF authorization, an authorization for two home assessments by a Home Health Agency (HHA) nurse, preferably experienced in evaluating the maternal/infant environment, can be separately authorized (4). We hope to provide follow up visits at home, after implementation of family physician program throughout the country.

We use from preterm babies' growth charts in HRIF service package instead of the Centers of Disease Control and Prevention (CDC) individual growth charts (10).

Our neurodevelopment evaluation tests and its time table conform to HRIF program of the Women and Newborn Health Service (WNHS) of King Edward Memorial Hospital, Australia; Perth (11). Comparing to California program, we considered ASQ screening test and Griffiths extended test instead of Denver II screening test and bayley extended test for neurodevelopment assessment. According to literature review and

decision of expert panel, Ages & Stages Questionnaire(ASQ) has been chosen as a screening test for detection of neurodevelopment disorders with 71-85%(overall 78%) sensitivity and 90-98% specificity (12). Griffith's test as a more specific and extended neurodevelopment test is used to investigate more closely, If ASQ test fails or the parents worry or the physician finds a doubtful point in his/her assessments. This method is also used in King Edward Memorial Hospital in Perth city in Australia (13, 14).

Regarding to importance of ECD and programming for its stages included survival, health and physical growth and development, especially in HRIs, the designed program, can help us to improve early childhood health, growth and development, since NICU wards have been expanded and child survival have been increased in Iran. We tried to support all of the three broad domains of early child development contribute to health, and have a key role in health equity, across the lifetime including physical, social/emotional, and language/cognitive dimensions in the designed service package. We also organized educational program to improve parenting knowledge and practice.

This program establishes the linkage between inpatient and outpatient HRI health services that is called continuity of care as a principle of health care services. Follow up for children who have required special care is an integral part of the continuum of their care.

We believe that implementation of the program through whole East Azerbaijan, Iran, leads to understanding its difficulties as well as defects that would be challenged to improving and developing of the program. Since training follow up team, plays an important and fundamental role in proper and successful implementation, it is necessary to design a curriculum carefully. We believe this program is a dynamic process and required to be evaluated annually or each two years. Analyze and interpretation of collected data, help us to notification our possible mismanagements in NICU wards and follow up clinics and improving them. We hope implementation the HRIF pilot study in East Azarbijan provience for the first time, help us be able to suggest a nationwide model for implementation of the program in the whole country.

Conclussion

We designed and finalized HRIF service package including clinical guidelines, executive program and family education plan as an action model for the whole country.

Ethical considerations

Ethical issues (Including plagiarism, Informed Consent, misconduct, data fabrication and/or falsification, double publication and/or submission, redundancy, etc.) have been completely observed by the authors.

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