JAHC | JOURNAL OF ADVANCED HEALTH CARE
OFFICIAL JOURNAL OF TSRM PSTRP

RESEARCH ARTICLE

Survey in the Campania region on follow-up services for premature infants

Pia Moliterni[1]*, Sara Panizzolo[2]

1. *Speech therapist Cieffemme, Naples*
2. *Speech therapist UOC Neonatal Intensive Care Unit , AO Monaldi- Naples*

Corresponding author: moliternipia@gmail.com

KEYWORDS:

Follow-up preterm infant, Outcomes preterm infant, Speech Therapist

ABSTRACT

Prematurity is not an extemporaneous event but a chronic condition that may manifest over time in a manner that is as severe as the earlier the birth. Therefore, the course of care cannot end at the time of discharge but necessarily continues over time with a clinical and affective relationship with young patients and their families. (WHO, 2015).

The purpose of this study is to conduct a cognitive survey of the state of the art of Preterm Infant Follow-up services in the Campania region; surveying their points of strengths and critical issues, and raise awareness among NICU managers of the importance of the resource enhancement to ensure its operation adheres to recommendations of organizational standards for perinatal care. The characteristics of the premature infant, possible neuroevolutionary trajectories, and the developmental outcomes associated with prematurity. The follow-up of the at-risk infant according to the recommendations of the organizational standards for perinatal care and the guidelines of the recent handbook "The Follow-up of the Preterm Infant. The First Six Years of Life," which is an important milestone in the perinatal clinic with the establishment of the services of Follow-up in order to ensure care pathways even after discharge.

The importance of the speech-language pathologist and his role in the Follow-up service team is emphasized, and the areas of assessment of oral-alimentary functions, communication, language, and learning are explored. Finally, the questionnaire used for the state-of-the-art analysis of Preterm Infant Follow-up services involving twelve out of seventeen Neonatal Intensive Care Unit departments in the Campania region was presented. The experience conducted for the compilation of this thesis allowed us to outline the importance of the speech pathologist in the Follow-up service team, to promote networked pathways with the territorial facilities and finally to ensure adequate Follow-up service in terms of appropriateness and effectiveness.

INTRODUCTION

The European Standards of Care for The Health of the Newborn (EFCNI, 2018) taken from the Guidelines of the Italian Society of Neonatology (SIN, 2021) include a special section dedicated to the Follow-up of the at- risk newborn (premature and/or medically complex) whose principles can be summarized as follows:

1. Risk identification for early detection of target populations and the specific areas of assessment
2. Multidisciplinarity/multi-professionalism and hospital-territory network construction
3. Information and support for parents/caregivers, in adherence to the Infantand FamilyCenterd-Developmental Care approach
4. Audits for data collection and development of strategies for 'implementation of neurodevelopmental models of care.

1. Risk identification

The scientific literature on the sudden therapeutic advances in the field of neonatal pathology recognizes several risk factors for neurodevelopmental outcome in preterm and term but affected infants; at the pre- peri natal stage they are identified by birth less than 37 weeks, extremely low birth weight, presence of intrauterine growth retardation (IUGR) and/or SGA birth, pre- and perinatal distress, lung malformations, congenital heart disease , outcomes from maternal infection or pathology (National Institute for Health and Clinical Excellence - Developmental Follow up of children and young people born preterm. NICE guideline Published: August 9, 2017); in the postnatal phase, the risk factors consist of those pathological conditions that often arise from the primary condition, and manifest during the first few weeks of life, such as pulmonary bronchodysplasia (BPD), retinopathy of preterm (ROP), hypoxic-ischemic encephalopathy, necrotizing enterocolitis (NEC) and short bowel.

2. Multidisciplinarity and hospital-territory network construction

At discharge from the NICU, the care of newborns with risk factors must be guaranteed by services possessing a broad multidisciplinary team capable of supporting, in a continuity of care, the complex health needs in order to ensure the best possible quality of life. In order to respond to the progressive needs of this segment of the pediatric population, Follow-up programs require multiple professional figures possessing specialized skills in order to direct them toward individualized care and rehabilitation pathways delivered by territorial services (in outpatient or home care settings).

RESEARCH ARTICLE

JAHC | JOURNAL OF ADVANCED HEALTH CARE
OFFICIAL JOURNAL OF TSRM PSTRP

3. Information and support for parents and caregivers

The family, already actively involved in inpatient care, is educated to continue its active role in the management of their child,even after discharge. The Follow up Team supports in guiding the path of care and rehabilitation at the Territorial Services, which in turn, in taking charge of the child, continues in the work of parental support on the emotional, educational and neurodevelopmental aspect. The model of care promotes and supports a FamilyCentered Service (FCS) approach, which has proven to be an indispensable tool for greater treatment compliance, from which derives a net decrease in parental stress, greater participation, an increase in skills useful for habilitative care and thus a better neurobehavioral outcome for the child. As reported by the European recommendations (EFCNI2018 ch 8.1) a FamilyCentered Care approach suggests the provision of specific training and supervision programs for all health professionals involved and educational programs dedicated to family support and education

4. Audit

The aim is to record the data needed to understand the evolution of the individual's medical history and to collect the data needed to understand the characteristics and outcomes of the population at risk. For this purpose, a national network(INNSIN Network) has been set up for computerized data collection and annual data processing. Analysis of the data provides the basis for initiating a nationwide comparison to identify positive aspects, critical elements and tools for improving clinical practice.

ORGANIZATION of the Follow UP

The recommendations define a Follow-up Service organized on two levels and provides for age-differentiated assessments.

LEVEL 1- Screening Level

The Clinical-Diagnostic Screening level (0-3 years) includes baseline assessments in the major motor, neurocognitive, behavioral, and neurosensory domains that must be performed in all children enrolled in Followup, regardless of the organizational level of the Follow-up service. Supports in a structured way the parenting intake and the assessment of parents' and children's Quality of life (QoL). Participates in the establishment of a territorial support network and the INNSIN Follow-Up Network.

LEVEL 2- Specialist level

The Specialist Clinical-Diagnostic level (after age 3) includes specialist evaluations reserved for children who need further diagnostic investigation or are part of specific research projects until adolescence.It also coordinates single-center and multicenter clinical research tracks in all specific areas of Follow-up and supports training tracks aimed at all health professionals involved.

Area of evaluation	**40 sg**	**3months e.c.**	**6-8months e.c.**	**12months e.c.**	**24-36 months**	**4-5 years old**	**6 years**
Growth	*	*	*	*	*	*	*
Nutrition-BMI	*	*	*	*	*	*	*
Neurological Examination	*	*	*	*	*	*	*
Functional assessment				*	*	*	*
Mental development tests				*	*		
Cognitive assessment						*	*
Motor assessment					*	*	*
Executive functions					*	*	*
Behavior				*	*	*	*
Visual function	*	*	*	*	*	*	*
Auditory function	*	*		*			
Language				*	*		*
Neuroimaging	*						
Cardio respiratory function in children with BPD	*	*	*	*		*	*
Evaluation Quality of life						*	

Fig.- 1 Timetable for Follow-Up

ORGANIZATION OF THE FOLLOW UP

The recommendations define a Follow-up Service organized on two levels and provides for age-differentiated assessments.

LEVEL 1- Screening Level
The Clinical-Diagnostic Screening level (0-3 years) includes baseline assessments in the major motor, neurocognitive, behavioral, and neurosensory domains that must be performed in all children enrolled in Followup, regardless of the organizational level of the Follow-up service. Supports in a structured way the parenting intake and the assessment of parents' and children's Quality of life (QoL). Participates in the establishment of a territorial support network and the INNSIN Follow-Up Network.

LEVEL 2- Specialist level
The Specialist Clinical-Diagnostic level (after age 3) includes specialist evaluations reserved for children who need further diagnostic investigation or are part of specific research projects until adolescence.It also coordinates single-center and multicenter clinical research tracks in all specific areas of Follow-up and supports training tracks aimed at all health professionals involved.

MATERIALS AND METHODS

TERRITORIAL SURVEY FOLLOW UP SERVICES CAMPANIA REGION

The study has the objective of investigating the state of the art of the Preterm Infant Follow-up services present in the Campania region. For this survey, a questionnaire was designed and sent to the seventeen Neonatal Intensive Care Units in the Campania region. (Fig.2)
The questionnaire consists of thirteen questions aimed at detecting the presence of the basic principles governing the Follow-up service and consequently raising awareness among the managers of the respective NICUs on the importance of strengthening structural and human resources for adapting to the recommendations of the Organizational Standards for Perinatal Care (EFCNI-SIN).The 13 questions that make up the questionnaire are given below.

1. Are there post-discharge follow-up services in your area?
2. How many days after discharge is the first follow-up performed?
3. Is there a control calendar?
4. If yes, how is the calendar structured?
5. What professionals are involved in follow-up services?
6. What screenings/assessments are conducted in the follow-up pathway?
7. Are there networked pathways with territorial facilities?
8. Follow-up continues until age 6 with assessments in the main areas(motor, neurocognitive, behavioral,neurosensory).
9. If not, up to what age is the child followed up?
10. Is the INNSIN follow-up network present?

Province of Naples	Salerno	Caserta	Benevento	Avellino
AO of the hills-Hospital Monaldi	AO San Giovanni di Dio and Ruggi d'Aragona	AO St.Sebastian and St.Anne's	AO Rummo-PO St.Pius	AO San Giuseppe Moscati
AOU Federico II	ASL Salerno-PO Umberto I (Nocera).	Pine Grove Nursing Home Great(Castle Volturno)	Sacred Heart of Jesus Fatebenefratelli Hospital	Villa dei Platani Nursing Home
AOU Vanvitelli	ASL Salerno-PO Santa Maria della Speranza (Battipaglia)			
AORN Santobono-Pausilipon				
Hospital-Madonna del Goodonconsiglio Fatebenefratelli				
Evangelical Hospital-Villa Betania				
Villa dei Fiori Nursing Home(Acerra)				
ASL Na 3 Sud PO San Leonardo (Castellamare di Stabia)				

Fig.-2 Neonatal Intensive Care Unit of the Campania Region broken down by province

11. Is there a connection with NIDA (Italian Network for the Early Recognition of Autism Spectrum Disorders) Clinical Centers ?
12. How do you evaluate the effectiveness of the follow-up service in your area or in your NICU?
13. Do you have any personal thoughts about the follow-up?

The "Google Forms" platform was used to fill out the questionnaire; it was sent to the NICUs Regional by e-mail address or presented in person at individual operating units 12 NICUs responded to the questionnaire 70.59 % out of the total of 17 in the Campania region.

RESULTS

The 'survey involved a sample of 12 Neonatal Intensive Care Units (out of 17) that answered the 13 questions in the questionnaire.

- Are there post-discharge follow-up services in your area? They answered: 83.3 percent YES and 16.7 percent NO.

2. How many days after discharge is the first follow-up performed? They answered 66.7% at 7-10 days after discharge, 33.3% at 40 weeks of age correct, no response for 2-3 months of age correct.
3. Is there a control calendar? They responded 100% for the presence of a control schedule.
4. If yes, how is the calendar structured? The responses were as follows:

- 3 /12 NICU follow LG of SIN recommendations.
- 2/12 NICU twice a month
- For VLBW infants O < to 32 ws there is an individualized schedule of more or less 1⁄2 one or two checkups
- per month
- Follow-up at 3-8-12-24 months
- A week
- On a monthly basis
- I don't know.

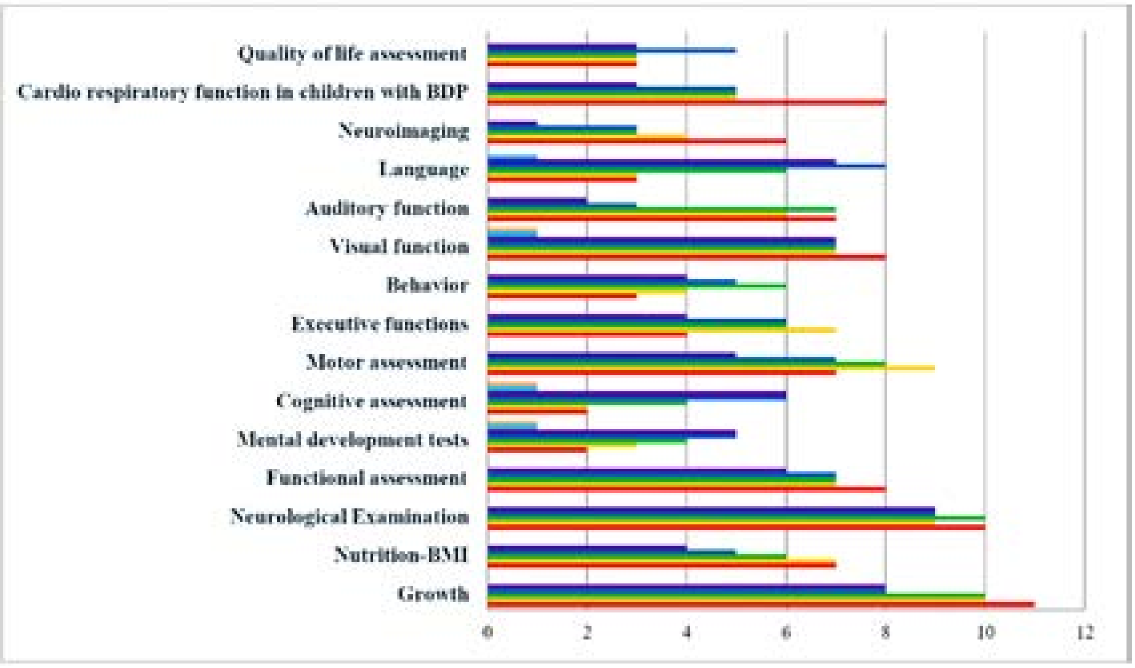
5. What professionals are involved in follow-up services?

-Percentage of 100% the Neonatologist, 46.2% the Child Neuropsychiatry, 30.8% the Physiatrist, 7.7% the Psychologist, Neuropsychomotricist, Neurologist, Pneumologist, Cardiologist, Ophthalmologist and Nutritionist, 15.4% the Physiotherapist and Speech Therapist, 84.6% the Nurse.

6. What screenings/assessments are conducted in the follow-up pathway? Responses are shown in the chart.

Evaluation of effectiveness of follow-up services.

🟧 6 years
4-5 years old
24 - 36 months
🟦 12 months e.c.
🟩 6-8 months e.c.
🟨 3 months e.c.



Growth	Nutrition	Neurologico exam.	Functional assessment	Mental development	Cognitive v.cognitive	V.motor	Executive functions	Comportamento	Visual F.	F. auditory	Languageso	Neuro imaging	Cardio respiratory f. in BDP	V.quality of life
				1	1				1					
				1	1				1		1			
8	4	9	6	5	6	5	4	4	7	2	7	1	3	3
8	5	9	7	5	6	7	6	5	7	3	8	3	5	5
10	6	10	7	4	4	8	6	6	7	7	6	3	5	3
10	7	9	7	3	2	9	7	4	7	6	3	4	5	3
11	7	10	8	2	2	7	4	3	8	7	3	6	8	3

7. Are there networked pathways with territorial facilities? They answered 66.7 percent for NO and 33.3 percent for YES.
8. Follow-up continues until age 6 years with assessments in the main areas (motor, neurocognitive, behavioral, neurosensory). They answered 83.3% NO and 16.7% YES.
9. Is the INNSIN follow-up network present? They responded 66.7 percent for NO, 16.7 percent for YES and is IN PROGRAM.
10. If no, up to what age is the child followed up? Of the 12 NICUs, 8 responded:
    - 0-2 years = 5 NICUs out of 12(41.6%)
    - 0-3 years= 2 out of 12 NICUs (16.6%)
    - > 3 years = 1 out of 12 NICUs (8.33%)
11. Is there a connection with NIDA (Italian Network for the Early Recognition of Autism Spectrum Disorders) Clinical Centers? They answered 16.7% YES and with 83.3% NO.
12. How do you rate the effectiveness of the follow-up service in your area or in your NICU?-considering a scale from 1 (mediocre) to 5 (excellent)-The responses were as follows:

13. Do you have any personal thoughts about the follow-up? -The answers were as follows:
    - Implementations with different professional figures
    - No, no consideration
    - It is not recognized at the regional level
    - It would be helpful to involve the social work side for those children/family who need to be cared for on the ground
    - There should be more synergy among the centers in the area network
    - Unfortunately, we have deficiencies that are beyond our control

DISCUSSION

The present survey on the state of the art of Preterm Infant Follow-up services in the Campania region provided important information on continuity of care:

- 12 out of 17 NICUs responded to the questionnaire: rate of 70.59% post-discharge follow-up services are present with a rate of 83.3% .
- a Interregional level The follow-up check-up schedule is uneven: only 8 NICUs follow the SIN recommendations: at 7-10 days after discharge, the first check-up is performed with a rate of 66.7%, the next multispecialty program is planned, the adjustment of the family and child to the home setting is verified, information exchange on territorial health services .
- mutiprofessional Team is predominantly composed of the Neonatologist (100%),the Nurse (84.6%), the Child Neuropsychiatrist(46.2%) and Physiatrist (30.8%)
- in the Follow-up Multidisciplinary Team the Speech Therapist is present in only 2 NICUs of the 12 responding to the questionnaire.
- For 83.3%, follow-up does not continue until age 6, and 5 out of 12 NICUs follow the child until age 2
- Networked pathways with other facilities are not present for 66.7%
- Linkage with NIDA Clinical Centers is present at 16.7 percent while 66.7 percent have not activated the INNSIN follow-up network
- On a scale of 1 (mediocre) to 5 (excellent), 7 out of 12 NICUs responded by giving a score of 3.

The recent European and national recommendations (EFCNI-SIN) are born with the intention of creating homogeneous models of care not only in inpatient settings but also in continuity of care: the monitoring of early developmental trajectories represents a 'strategic action for improving the quality of life of children with foreseeable neurodevelopmental disorders and their families. Continuity of care, assessment of short- and long-term clinical outcomes, rehabilitative interventions at an early age, and analysis of 'effectiveness represent the main objectives of Follow-up programs and configure a new clinical neonatal frontier , closely linked to research for the planning of maximally effective care-therapeutic-rehabilitation models.

Multi-specialty evaluations within three years of a child's life mainly intercept major disabilities (e.g., infant cerebral palsy, mental impairment, blindness), while identification of disorders considered minor requires prolonging the evaluation at least until the beginning of school age. Even with the relative improvement in the survival of extremely young children for gestational age (24-26 weeks), the prevalence of clinical and neuropsychiatric problems has in fact increased significantly over the past decade: neurodevelopmental disorders, in particular, account for a significant proportion, in terms of incidence and possible impact on future quality of life. For this reason, in the current view, prematurity is increasingly equated with a chronic disease. This recommendation is supported by data from the literature regarding the recognition of additional possible minor outcomes such as sensory disorganization, attention disorders , memory deficits, and difficulties in executive functions and school learning. (Allotey J, Zamora J, Cheong-See F, Kalidindi M, Arroyo-Manzano D, Asztalos E, van der Post J, Mol BW, Moore D, Birtles D, Khan KS, Thangaratinam S. (2018), Cognitive, motor, behavioral and academic performances of children born preterm: a meta-analysis and systematic review involving 64 061 children. BJOG125(1):16-25.)

There is still a need to create greater synergy between the first-level centers and the territorial network in the continuity of care phase.

It is extremely important to activate the INNSIN Follow-up registry, a fundamental tool indispensable to the collection of data on the development of preterm infants, take a snapshot of the reality of the NICUs throughout the country and implement projects aimed at improving pediatric care. Greater promotion of a clinical and scientific network in order to detect developmental atypia early is essential, which is why the establishment of the link between NICUs and NIDA clinical centers is important.

In conclusion, the research project on the state of the art of the NICUs in the Campania region shows an uneven situation in the adherence to recommendations and reports organizational differences as found in the national territory but also in the various countries throughout Europe (Standards of Care for the Health of the Newborn (EFCNI,2018) .However, it is encouraging the remarkable and steady progress of neonatology , a discipline albeit recent but constantly engaged in scientific research and in the construction of therapeutic-welfare models aimed at improving the outcomes of the fragile newborn, along with improving the quality of life of the entire family.

BIBLIOGRAPHY

1. *European Foundation for the Care of Newborns Infants. European Standards of Care for Newborn Health: Follow-up and continuing Care. 11/2018.*
2. *Italian Society of Neonatology-Task Force on the Follow-up of the Preterm Infant- Indications The Follow- up of the Preterm Infant in the First Six Years of Life. 2022 Edition.*
3. *Vollmer B, Stålnacke J. Young Adult Motor, Sensory, and Cognitive (2019), Outcomes and Longitudinal Development after Very and Extremely Preterm Birth. Neuropediatrics. 50(4):219-227.*
4. *Guarini, A. Sansavini, A. Fabbri, C. Savini, S. Alessandroni, R. Faldella, G. Karmilo, Smith, A. Long-term effects of preterm birth on language and literacy at eight years. J. Child Lang. 2010, 37, 865-885.*
5. *Organizational Standards for Perinatal Care IdeaCpa Publisher ©2021,Rome Printed I Edition in May 2021 by Yoo Print S.r.l. - Gessate (Milan) ISBN 978-88-946-318-90*
6. *First 1000 Days the critical WinDoW to ensure that chilDren survive anD thrive May 2017*
7. *Chericoni, N., Balboni, G., Costanzo, V., Mancini, A., Prosperi, M., Lasala, R., Tancredi, R., Scattoni, M. L., NIDA Network, Muratori, F., & Apicella, F. (2021). A Combined Study on the Use of the Child Behavior Checklist 11/2-5 for Identifying Autism Spectrum Disorders at 18 Months. Journal of Autism and Developmental Disorders, 51(11), 3829- 3842.*
8. *SIN. National Knowledge Survey on Follow-up Services of the Preterm and/or At-Risk Newborn. Edited by F. Gallini, C. Gizzi, F.Fulceri, ML Scattoni, M. Fumagalli. IDEA cp , Rome, 2019*
9. *Vermont Oxford Network - VON ELBW Infant Follow up Project.*