

UCPP PROGRAM:

VENTILATION ASSISTANCE UNIT AT HOME

Introduction

In the world, an emerging population of children is described, with complex characteristics that require special health care, due to the multiple morbidities of those who are carriers. These children are known as Complex Children, or Children with Special Needs of Attention (NNEA).

This emerging population is made up of those children who have survived due to the advancement of science and technology, but who require special help to maintain an acceptable quality of life.

Many of them are carriers of rare or orphan diseases such as metabolic, neurodegenerative diseases, whose main characteristic is that they are chronic, disabling and life-limiting.

Another group of children is made up of those with sequelae of serious or catastrophic diseases, such as Infant Cerebral Palsy, sequelae of serious infections or accidents, whose quality of life is affected, but who are able with special help to reintegrate into their social environment.

Finally, there is a third group, those who are born with significant congenital malformations, who, having received or not the help of medical science, require support in order to continue living in a dignified way.

Many of these children, as a consequence of the complex problems, need some technological aids such as Tracheostomy and Gastrostomy, and their mothers are their most important caregivers, who receive training to be able to provide their children with the required care in

their own homes, with in order to preserve their health without having to frequently resort to a health facility.

Among the technological requirements in these children are respiratory support technologies. Respiratory support can range from the simplest to the most complex, from continuous oxygen delivery or not, to non-invasive ventilatory support. It is able to provide these at home, with adequate supervision, in order to have children and their caregivers with quality of life.

The actual option is to try to provide the necessary home support, in order to contribute to achieving the best possible quality of life, maintain family ties, achieve adequate socialization, and allow their inclusion in schools, thereby achieving personal and social development of children, and their families.

Until a few years ago, the situation of these complex children, not programmed in health establishments, was problematic. These patients were progressively occupying the hospital facilities, with prolonged hospitalizations and a great risk of acquiring intrahospital infections, but above all it deprives them of having a loving environment and inserting themselves in the society.

The significant increase in the prevalence of these complex children with special health needs, was important in developed countries, and motivate us to the search appropriate strategies that would allow them to return home, to have the technology for their correct care at home, and at the same time reduce the costs of care and improve the quality of life.

One of the most important support required was respiratory support technology, and they have evolved and now there are available for home care, like low and high flow oxygen therapies, CPAP type ventilators (Continuous Positive Airway Pressure, and Bipap type (Biphasic ventilators), which have changed the life outlook in many children with respiratory restrictions. These are named Non-invasive mechanical ventilation (NIMV)

NIMV helps children with primary or secondary respiratory failure, due to pulmonary failure or obstruction of the upper airway like in obstructive sleep apnea, by establishing positive pressure support applied by means of a mask.

Ventilatory assistance is now possible to do at home which has proven to benefit and contribute to the quality of life of these complex children

The Pediatric Palliative Care unit of the National Institute of Child Health - Lima, Peru, has been developing a Home Ventilatory Assistance Program, which benefits children who have respiratory failure that can be treatable with adequate medical devices for use at home. Some necessary requirements to these children are to have respiratory autonomy.

We currently have 15 children with support with Non-Invasive Ventilators, 14 at home, one in the hospital. Some of them additionally with oxygen therapy provided through oxygen concentrators, and others only with oxygen support (6 of them).

Home Ventilatory Assistance Program

This Program includes those activities that range from the evaluation, diagnosis and therapeutic proposal that will benefit the child who suffers from diseases with respiratory failure. We do not know exactly the prevalence of home ventilatory assistance needs for children in our country, as there are no statistics in this regard. At the National Institute of Child Health (INSN), being a national reference center, it centralizes most of the care of these children.

In the INSN, for approximately 20 years, the number of children with ventilatory support has been increasing, with approximately 30-35% of Intensive Care beds occupied by patients with Prolonged Invasive Mechanical Ventilation. Most of these children are hospitalized out of the Intensive Care Unit.

We know that there is a larger group of patients with multiple chronic diseases who need of non-invasive Ventilatory Support, and it can be done at home with the advantages already described.

The Comprehensive Health Insurance (SIS) recognizes the care provided by our Pediatric Palliative Care Unit, as well as providing the medicines and supplies necessary for the care of children, which constitutes a real advantage in solving the problem.

Operational definitions

- Non-invasive Mechanical Ventilation (NIMV): It is all ventilatory support that is provided to a patient through flow-generating equipment with positive pressure delivery in the airway. It is intended to reduce the workload or complement the ventilatory function in patients with respiratory pump failure and / or Obstructive apnea syndrome.
- CPAP: Ventilatory support modality applying continuous positive pressure in the airway.
- BiPAP: Ventilatory support modality applying two-level positive pressure in the airway.
- Event: It is any deviation in the usual clinical behavior of the observed patient, in relation to ventilatory support.

Goals

The main objective of the Ventilatory Assistance program at home (VAPH) is to provide the necessary ventilatory medical support to those patients who require it with appropriate devices, and contribute to improving their quality of life, and increase the resolution capacity of the healthcare network.

Specific objectives:

- a. Training for caregivers in the adequate home care of patients in need of ventilatory support.
- b. Reduce the morbidity and mortality of patients with diseases that lead to respiratory failure, through the appropriate use of ventilatory support at home.
- c. Strengthen the management capacity of Health Care Facilities, through pediatric palliative care at home.
- d. Optimize the hospital resources in special in pediatric intensive care units, allowing the admission of more patients with severe illnesses.
- e. Optimization of the resources of the Health System through the attention of these patients on an outpatient basis, with a high cost-benefit performance.

Beneficiaries of the Home Ventilatory Assistance Program:

- The program is directed to those patients whose diseases indicate that they merit chronic non-invasive ventilatory support.
- They are in a stable clinical condition with respiratory autonomy while awake.
- They have type II respiratory failure (hypercapnia) without respiratory acidosis.

- They could need oxygen requirements less of 3L/ min to keep a oxygen saturation > 92%.
- They have a responsible adult caretaker committed and with a social network

It is important to have an informed signed consent and a loan contract (borrowed or ceded for use) of the respiratory device equipment duly signed by the responsible caretaker

The home has to have basic services and adequate installations (electricity, indoor water, easy house access, telephone)

Inclusion Criteria

Patients who required be included in the program, could have some of these problems:

- Patients with pulmonary problems like Bronchopulmonary Dysplasia, Acute Cystic Fibrosis, Obliterate Bronchiolitis.
- Patients with central ventilatory failure, or thoracic problems or neuromuscular problems, neuromuscular illnesses and congenital myopathies. Muscular dystrophy, type 1 and 2 spinal atrophy, Duchenne disease.
- Patients with obstructive sleep apnea: morbid obesity, hypotonia or craniofacial malformations.
- Patients with chest wall disease (Xiphoscoliosis, etc)

And with at least one of the following criteria:

- a. Nightly record of Oxygen Saturation <90% in 10% or more of sleep time. Oximetry record required at least 8 hours.
- b. Oxygen Saturation <90% greater than 20 sec. For 5 or more times in one hour record.
- c. Pulmonary Vital Capacity <50%.
- d. Arterial gasometry PaCO₂> 50 mmHg, EB> 4mEq / l

Exclusion criteria

Children that no benefit of the program:

- Failure to comply with the social evaluation criteria referred to in Program Beneficiaries
- Total lack of tolerance to the interface (mask)
- Rapidly progressive neuromuscular disease (Type I spinal muscular atrophy)
- Swallowing disorder with lack of glottic protection
- Need for ventilatory support for more than 10 hours or absence of respiratory autonomy.
- Be under 6 months

- Cerebral palsy

Activities

1. Training for caregivers:

- a. Training for caregivers on the care of their children, which includes training in respiratory physiotherapy, basic physical therapy, training in tracheostomy care and feeding by nasogastric tube or gastrostomy
- b. Training for caregivers in aspiration of secretions and nebulization.
- c. Training for caregivers in the proper use of ventilators (Bipap or Cpap), oxygen concentrators, or other biomedical equipment that the patient requires to maintain ventilatory stability.

2. Diagnosis:

- a. Evaluation of compliance with inclusion criteria (at least one test indicative respiratory failure), including social and psychological evaluation.
- b. Evaluation to determine ventilatory support modality: Oxygen therapy, CPAP or BiPAP.
- c. Start of Ventilatory Support in Hospitalization to see patient adequacy and caregiver training.

3. Entry Protocol to the NIMV program at home:

- a. An interconsultation is generated with the Pediatric Palliative Care UNIT (PPCU) for evaluation and request of ventilatory support to the patient.
- b. A medical evaluation is carried out (it can be complemented by consultations with other specialties, eg neurology, cardiology).
- c. Respiratory functional tests (Inclusion Criteria) are performed to choose the Ventilatory Support modality.
- d. NIMV test in the patient: response to ventilatory support, patient adaptability.
- e. Social Assessment
- f. Informed Consent Signing for NIMV at Home
- g. Signing of the Loan Agreement (Assignment of use) biomedical equipment

- h. Caregiver Training
- i. Caregiver competency assessment
- j. Contact with the Primary Care Network close to the patient's home

4. Outpatient and Home Monitoring:

A. Periodic controls of patients, either by Outpatient Consultation, and also by Home Visit, by the PPCU team:

a. Appointment outpatient care, to verify status and supply with supplies and medications monthly.

b. Home visit schedule (every 15days) for a month, then monthly.

c. Telephone calls every week (first month) to see adaptability to the program, then each 15 days.

B. Detection and treatment of Respiratory Events or Contingencies: filling out a special form)

C. Permanent telephone service and on demand.

D. Training for primary and secondary care facilities to help control interurrences at home and emergency care.

Human Resources:

Pediatrician or Pediatric Pulmonologist specialized in Respiratory Therapy and Palliative Care

Nurse with training in Respiratory Therapy and Palliative Care

Respiratory Therapist with experience in Ventilatory Assistance

Psychologist with experience in Palliative Care

Social Worker with experience in Palliative Care

Nursing Technician

Indicators:

1. Patients admitted to the Program per year

N° of admissions per year to the NIMV Program / Total number of patients applied to the Program in one year

2. Staff (Trained Caregivers)

a. N ° of Caregivers trained in NIMV / Total Caregivers of the UCPP

3. Optimization of beds

N ° of hospitalization days during the year of patients in the NIMV Program / Total patients in the NIMV program per year

Requirements:

For the correct care of patients in need of ventilatory support, the following equipment and supplies are required:

Equipment

- BiPAP equipment (Bi-level fans), for children from 5 kg of weight, and adults, with thermohumidifier, and battery with autonomy of at least 4 hours
- Cpap equipment, for children from 5kg in weight and adults, with thermo humidifier, and battery with autonomy of at least 4 hours
- Assistant cough equipment
- Oxygen concentrators 1-5 liters / min, and 1-8 liters / min.
- 1-2 m³ oxygen tanks with valve and humidifier, for transport.
- Self-inflating resuscitation bag
- Home-use secretion aspirators
- Nebulizers for home use
- Home use digital pulse oximeters

Supplies:

- Naso-orofacial mask various sizes
- Nasofacial masks various sizes
- Exhalation Valves (for children with tracheostomy)
- Filter for tracheostomy tube
- Reusable Corrugated Tubes
- Mount-type straight corrugated tubes

- Corrugated tubes in T
- Tracheostomy nebulization set
- Pediatric and adult nebulization set
- Aspiration Probes (different numbers)
- Protection gloves
- Non-conductive tube
- Syringes of different sizes
- HME filter (for use in respiratory systems) adult and pediatric

Medications needed:

- Physiological serum
- Salbutamol (drops or inhaler)

Main Costs Equipment and supplies (Equipment for the care of 25 patients + contingency equipment. Supplies: annual requirement)

Request (*)

Costs

10 BiPAP (Mod. Dream Star - Adult- Pediatric)

\$ 3850 (S/. 14245)

Total US **\$ 38500** (S/. 142 450)

Naso facial mask Pediatric Size (S-M-L), Adult (S-M-L)

20 of each

\$ 105 (S /. 400 ea)

Approx. **Total \$ 2100** (S /. 7770)

Naso-oro-facial mask Pediatric Size (S-M-L) and Adult (S-M-L)

10 of each

\$ 105 (S /. 400 ea)

Approx. **Total \$ 2100** (S /. 7770)

Exhalation valve (for Tracheostomized Pac.)

10

\$ 80 (S /. 300)

Total **\$ 800** (S /. 2960)

(*) Priority: Shaded equipment and supplies.

Total prioritized teams \$ 43 500 (S /. 160 950)

Costs Medications and supplies Monthly (These are provided by the Health care facility)

Monthly Total: S/. 245.55 (\$ 70)

Cost Structure:

If we calculate the annual cost of the equipment (List 1), then monthly, with an approximate annual depreciation calculation for each of them - BIPAP (5 years), and consider other devices like nebulizers and secretion aspirator (2 years), pulse oximeter (1 year), masks (6months) and we add the expenses in medicines and supplies, it gives us approximate a cost of S /. 700.00 per month per patient in NIMV - BIPAP at home. These will be the costs to be reimbursed by the SIS for the provision of the service. It has not been considered Personal as this is not reimbursable by the SIS.

Calculation of the monthly cost for NIMV-CPAP S /. 419.00 approximately.

Financing

The Program will be financed with the resources generated by the SIS consideration, and from the budget assigned to the INSN-Breña for the acquisition and replacement of biomedical equipment and for their preventive and corrective maintenance.

The resources will be used to finance the activities related to the program, as well as those related to the maintenance of biomedical equipment, medicines and supplies necessary for the provision of patient care.

Annexes:

- Informed Consent for Parents or Caregivers, for the Home NIV Program
- Loan Agreement (assignment in use) of biomedical equipment for Home NIV Program
- Medical file of a patient with NIMV, for information purposes in emergency cases.
- Format for changing supplies at home
- Home visit plan
- Procedures training test for caregivers: care of tracheostomy, gastrostomy, aspiration of secretions, use of oxygen concentrator.

Virginia Garaycochea Cannon and collaborators

Jan 15th 2020