

## Home Simulation Day for New Home Ventilated Children

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The number of patients requiring home mechanical ventilation has evolved over years and it is growing [1]. In the United States, long-term care of ventilator dependent children with their family, in the home environment, dates from the 1970s and 1980s, when portable ventilators became practical for home use [2].

Infants and children with chronic respiratory failure are byproducts of pediatric intensive care medicine improvement and home mechanical ventilation for stable patients has emerged as alternative to long intensive care unit stay, limited number of pediatric ICU (PICU) bed, high cost and for better quality of life for both family and patients [3-5].

Data suggest that the use of home mechanical ventilation will rise because of the documented benefits to patients and the economic pressure to shorten hospital stays [4]. It is extremely important to ascertain maximum patient safety and quality of life when shifting patient from intensive care unit within the hospital to intensive care at home. This will need proper preparation, multiple trained in-home caregivers, social support and ready access to medical care. It is a new experience for the family and a very challenging decision to transfer a ventilated child to home who requires intense care, multiple equipment's, adjusted home settings and at risk of adverse outcomes.

Home health services and home nursing services are not available in all places and there are substantial variations between countries and variations within each country in the available community health services [6]. Families face extreme emotional and social burdens [7] but in the other hand describe deep and enriching experiences that they do not regret in providing good care for their loved ones [8].

With limited home health and social care services and unavailability of home nursing services in our area, I believe caring of a ventilated child at home is surrounded with an overwhelming clinician and family responsibilities, risks, family anxiety and fear. Therefore, we developed pediatric home ventilation team with multiple subspecialties that work together to provide support for the patient and the family pre and post transfer to home. One of the main aim of the team is to prepare the family very well and to facilitate safe transfer to home and this cannot be achieved without high competency of multiple home caregivers and to alleviate their anxiety and fear. As we know that the care at home will be solely the responsibility of the family, we ascertain good family education and the child is not discharged home unless the family pass numbers of competency checklists. We use different teaching techniques and simulation is one modality for family education. We developed a new idea to simulate home care in the hospital before home transition in order to assess readiness of the family.

Home Simulation day is when the patient who is planned to go home with tracheostomy and/or ventilation is shifted from intensive care or high dependency unit to the general ward one or more days before going home during which the full care is given by the family as they are at home. The clinicians will be monitoring and supervising only to assure that the care provided by the family in a simulated home environment - while they are still in hospital- is satisfactory and they are competent and safe to go home.

During home simulation day, we shift the child and family to a low dependency bed and we facilitate the presence of at least two caregivers mostly father and mother or any other caregivers decided by the family.

The child must be kept in all home equipment's according to his/her condition including ventilator, suction machine, oxygen concentrator and home saturation monitor if needed. The patient should not be connected to continuous hospital monitor but routine check of vital signs is done according to the ward policy which is usually every 4 - 6 hours.

Home simulation day should not be done before caregivers pass all competency checklists that are assessed by pediatric home ventilation team and should not be done unless the patient is ready to go home from medical point of view. All home equipment's must be ready and working well and the family are confident to use them.

It is difficult for families to fully understand this new and a huge lifestyle adjustment before they have experienced it [9]. Home simulation day allows the family to experience it in a safe environment. It gives them the opportunity to perceive the nature of home ventilation care when they provide the full care independently while they are still surrounded by support and help if needed. It enhances the family confidence to take care of their child alone and decreases their anxiety and fear to go home. In the other hand it dictates to the medical team the readiness of the family to take care of their ventilated child alone and to assess their skills, reaction, competency and independence in order to ascertain safe home transition. It is a chance to know the areas that need more training and to allow the family to ask questions or to discuss any emerging concerns that may did not come up previously when the care is shared between them and health care team while the patient in intensive or high dependency unit. We believe that home simulation day plays a vital role from different aspects in safe home transition of a newly home ventilated children.

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