

## CASE REPORT

# The new normal: chronic stay in the paediatric ICU

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## Abstract

Advances in treatment options have resulted in a growing population of children who require chronic medical support in order to survive: children with medical complexity (CMC). Their complex medical needs are not easily met outside the hospital. The gap between the protective hospital environment and home proves to be extensive, which is why it is extremely challenging for this particular group of patients and their families to make that transition. In this case report, on the background of a child with medical complexity who endured an extremely lengthy admission to the paediatric intensive care unit (PICU), we will elaborate on the changes that are occurring in PICUs worldwide due to the growing CMC population as well as a transitional care unit as a possible intervention for this pressing issue.

## Introduction

Over the last decades the characteristics of patients admitted to the paediatric intensive care unit (PICU) have been subject to change. Advances in treatment options have resulted in decreased in-hospital mortality rates, also for patients with diseases that were previously considered to be incurable.<sup>[1]</sup> As a consequence, the number of children with medical complexity (CMC) has increased considerably in PICUs worldwide.<sup>[2, 3]</sup> These patients often require 24/7 supervision and rely on medical technology such as monitoring devices, respiratory support, gastrostomy, feeding pumps or tracheal cannulas.<sup>[4, 5]</sup> The transition from hospital towards home for these children, but also for those with medical complexity admitted to high care wards, is a particular challenge for both parents and professionals. As a result, CMC may experience lengthy PICU admissions and once discharged, their medical fragility and often instability puts them at risk for

complications necessitating frequent (PICU) readmissions.<sup>[6, 7]</sup> All in all, this situation poses a great burden on the healthcare system, the patient and caregivers, and society as a whole.<sup>[8]</sup>

Here we present a characteristic PICU case involving a chronic complex condition and technology dependency and the challenges that arise in the care for such a complex patient. Subsequently, we will reflect on possible solutions to improve the care of this growing intensive care population.

## Paediatric case

A 2-month-old girl was transferred from the neonatal ICU to our PICU because of axial hypotonia and refractory respiratory insufficiency, a condition which necessitated invasive mechanical ventilation. The respiratory insufficiency was caused by a diaphragm paresis of unknown origin, despite extensive investigations into the underlying cause. Despite plication of the diaphragm she remained dependent on invasive respiratory support which is why, at the age of 4 months, a tracheostomy was performed. During the ensuing months numerous attempts to wean her off the ventilator, including an inspiratory muscle training program, were unsuccessful. These attempts were often accompanied by 'spells', which caused deep desaturations requiring acute interventions, such as extra oxygen and balloon insufflations. Her psychomotor development stagnated, for which the paediatric rehabilitation team was consulted and multidisciplinary rehabilitation treatment was started. With extensive medical, nursing, and psychological support to both the patient and her parents, her situation slowly ameliorated and stabilised. Nevertheless, she remained continuously dependent on the ventilator from which, after ten months, she could be disconnected for a maximum of

30 minutes. It was only at this point that we considered it safe to work on her discharge from the PICU in collaboration with the institute for home ventilation. We started a training program for the parents to ensure the necessary medical knowledge and nursing skills. The parents are originally from Iraq and have lived in the Netherlands for over 10 years now. They have two older, healthy daughters aged 6 and 8 years and live about 30 kilometres from the hospital. Even though the parents were very much committed to the care of their daughter, it turned out to be a great challenge to empower them to take the lead in all aspects of care at home, such as medical, nursing, logistical and psychosocial affairs. The fragmented Dutch healthcare system proved to be extremely difficult for them to navigate and comprehend. The complexity of their social situation, the language barrier and their cultural background likely impeded this process of parental empowerment. The differences between the 'protective' hospital environment and their isolated home where they are their daughter's primary caregiver, proved to be large and difficult to overcome. Eventually, after an admission that lasted more than 18 months, the patient was discharged from the PICU. Initially, to bridge the gap between the PICU and home, she stayed at a paediatric nursing home half of the time. Within one month, in which the parents had time to catch their breath and finalise all affairs at home, they were able to take their daughter home fulltime.

## Discussion

Here we present a case that is exemplary of a technology-dependent PICU patient with a complex chronic condition who has passed the period of acute critical illness that is followed by a prolonged period of life-sustaining therapy from which she could not be weaned. As technologies improve, children like our patient with chronic medical complexity, such as congenital or acquired multi-system disease and severe neurological or metabolic illnesses, nowadays survive. This group is growing in number, as is their average lifespan.<sup>[9, 10]</sup> Over the last decades there has been an overall change in decision-making regarding appropriateness of offering life-sustaining therapy in an intensive care unit, with an increasing number of patients receiving this care. Many of these patients depend on medical technology and specialised nursing care for years, some even indefinitely. However, these technical medical achievements come with responsibilities and pose ethical challenges to the professionals. Quality of life is always the context in which any treatment or life-sustaining therapy should be considered.<sup>[8]</sup> Once the acute phase of the critical illness has passed, but the patient still relies on 24/7 intensive care or even remains technology dependent, the focus shifts from cure to specialised nursing care without (daily) involvement of the intensivist. Traditionally though, intensive care units are not designed to care for chronic, relatively stable patients. The increased use of life-sustaining therapies has resulted in many organisational

and logistical difficulties, in addition to the abovementioned ethical challenges.<sup>[8, 11]</sup>

First, the gap between a trusted PICU and home is large, which results in prolonged admissions that disrupt daily family life enormously. Moreover, the PICU environment is hardly an optimal setting for children to develop and reach their full potential. This is not the right care at the right place and the focus should be to transition home as soon as possible, once the patient is stable and chronic supportive treatment has been set up.<sup>[5, 12]</sup> However, the transition from the university hospital (where a team of professionals led by a physician is in charge and a nurse is available 24/7) towards home (where parents are the most important caregivers and managers of all the professionals involved) is a major challenge and often unsuccessful.<sup>[6]</sup> In order to make a sustainable transition parents need to be empowered. They must comprehend all domains of care that accompany chronic complex care. This process is ambitious and time consuming and requires support in all domains from relevant professionals: a comprehensive coaching role that many professionals are not used to fulfil. Parents have to learn technical skills and complex nursing care. Furthermore, they need to achieve self-confidence, improve self-efficacy, stay motivated and be able to continue to take care of the patient's siblings as well. Parents may experience stress, anxiety as well as incompetence, and often become isolated after discharge home, with frequent readmissions as a result.<sup>[7, 9]</sup>

Second, the occupation of acute intensive care beds by chronic intensive care patients interferes with the ICU capacity.<sup>[13]</sup> Finally, the increase in the number of chronic intensive care patients who endure lengthy admissions and frequent readmissions puts an enormous burden on hospital resources, a trend that has been observed worldwide in recent decades.<sup>[10, 14-16]</sup> In a retrospective study, Chan et al. even demonstrated that children with complex chronic diseases accounted for half of the PICU admissions in the US, but for over 75% of all PICU resources.<sup>[17]</sup>

Taking all of this into account, there is an urgent unmet medical need. In the age of personalised healthcare which includes innovative diagnostics and treatment strategies, we must now also tailor care for those who survive previously fatal conditions and are destined to require 24/7 intensive care for their medical complexities. It is time to revolutionise the hospital to home trajectory for fragile CMC and their families.<sup>[18]</sup> This process should take as little time as possible while remaining sustainable. The PICU should not become their second home. They deserve a more holistic approach in which all domains of care and family functioning are covered. Although existing facilities such as paediatric nursing homes provide adequate medical and nursing care, they often lack structured interventions aiming at the transition home and are not in close care collaboration with

hospitals. Intramural transition programs on the other hand may be less efficient to prepare parents for 'the real world' of being at home with their child. One way to improve the transition process could be to create a transitional care unit. A stand-alone unit, in close proximity to the hospital, as a safe environment where medical, nursing and rehabilitation care is guaranteed and where parental empowerment can be achieved. A place where parents can learn to manage their child's care within the family context earlier in the transition process. Interdisciplinary teams in these units that cover all child and parental needs, as well as disparate services and care providers, will optimise a sustainable hospital to home transition. Whereas much of the care involves non-medical issues like processing referrals, troubleshooting psychosocial issues, dealing with public health services and - in case of paediatric patients - consulting with schools, we believe that CMC and their families will benefit immensely from an intermediate step between hospital and home. This comprehensive way of providing care may alleviate the financial burden intensive care units encounter nowadays, but – more importantly – improve patient outcomes, reduce adverse events, empower parents and support families.

### Disclosures

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