Residência Pediátrica
Publicação Oficial da Sociedade Brasileira de Pediatria

Submitted on: 29/04/2020
Approved on: 07/07/2020

ORIGINAL ARTICLE

Checklist for the dehospitalization of pediatric inpatients with complex chronic conditions treated in the Brazilian Public Health Care System

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Keywords:
Patient Discharge, Pediatrics, Chronic Disease, Brazilian Public Healthcare System, Checklist.

Abstract

Pediatric intensive care units in Brazil are currently overwhelmed and filled with clinically stable patients who are chronically dependent on different medical technologies. These patients are categorized as having complex chronic conditions. In an attempt to humanize care, minimize complications, and decrease care costs, dehospitalization has been regarded as an option for this group of patients. Existing flaws in the dehospitalization process can be minimized through well-planned action. This study aimed to develop a checklist for the dehospitalization of pediatric patients with complex chronic conditions seen in hospitals working with the Brazilian Public Healthcare System to help healthcare workers organize the safe discharge of these patients. A literature review was performed between February and August 2019 to support the development of the checklist. Articles published from 2005 onwards with full-text available on medical databases (PEDro, PubMed e Lilacs) were searched based on the following keywords: Alta do Paciente (*Patient Discharge*), Doença Crônica (*Chronic Disease*), and Pediatria (*Pediatrics*). Simple literature reviews and articles covering adult populations were excluded. The checklist describes the involvement of each healthcare worker in the dehospitalization process. Healthcare workers must be acquainted with this new condition in order to educate patient families/caregivers about the measures required to provide for a safe discharge and prevent early hospital readmission.

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DOI: 10.25060/residpediatr-2022.v12n2-306

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INTRODUCTION

Brazil has undergone an epidemiological transition in recent decades in the form of changes to the causes of disease. This is a global trend that reflects changes in lifestyle, populations, urbanization, access to health services, diagnostic tools, and treatment.[1]

In the pediatric population, increases have occurred in the survival rates of preterm infants and children with congenital anomalies or genetic syndromes. Individuals with conditions once deemed untreatable now have a chance to prolong survival, often via the intensive use of medical technologies and care.[2]

In order to identify and develop better management practices for this patient population, the term complex chronic condition (CCC) was coined to include children and adolescents with functional, mental, and organ limitations lasting for at least 12 months that require specialized medical care and hospitalization at a tertiary referral center.[2] Furthermore, these patients have irreversible conditions and, therefore, require the involvement of healthcare teams along with parents and caregivers.[3]

This scenario is further affected by an overwhelming demand for healthcare services, which entail higher costs to hospitals and families.[4] According to Silva and Fonseca (2019), 65% of the patients with a CCC that had to be hospitalized once, needed to be hospitalized at least another time within a year. This illustrates the point that chronic disease often leads to dependence on medical technology and delayed patient dehospitalization.[2,5]

However, a trend towards dehospitalization and continuation of care at home has been observed. According to the Brazilian Ministry of Health (2012), dehospitalization introduces a number of potentially positive effects, including the humanization of care, additional comfort to patients and families, minimization of complications, and increased availability of hospital beds.[6] In order for dehospitalization to occur safely and effectively, three elements must be considered: the scientific-practical (the involvement of healthcare workers in these cases), legislative, and administrative spheres (costs incurred in by hospitals and homecare providers).[7]

This study aimed to develop a checklist to be used by multidisciplinary care teams for the safe dehospitalization of pediatric patients with complex chronic conditions offered treatment via the Brazilian Public Healthcare System.

METHODS

A literature review was performed between February and August 2019 to support the development of the checklist. Articles published from 2005 onwards with full-text available on medical databases (PEDro, PubMed e Lilacs) were searched based on the following keywords: Alta do Paciente (*Patient Discharge*), Doença Crônica (*Chronic Disease*), and Pediatria (*Pediatrics*). Simple literature reviews and articles covering adult populations were excluded.

RESULTS

Checklists are needed in effective dehospitalization to prevent the multidisciplinary care team from missing or neglecting items that are required for patients and their families/caregivers to transition into a new care reality, without undergoing deterioration of clinical conditions or increases in hospital readmission.

The checklist (Table I) covers the main topics healthcare teams working in pediatric intensive care units need to consider so that dehospitalization is advantageous not only to patients, but also to hospitals and society.[8]

The process includes steps such as grading the level of involvement of the patient (via supplementary tests and assessment of medical criteria); assessing the psychosocial status of the patient and their family/caregivers; assessing the environment in which the patient lives and household income level.[9]

Concurrently, the psychology team must check the psychological status of the patient's family and their thoughts about taking the patient back home with them, and follow them up throughout the discharge process.[10]

Nurses are usually closer to patients and families and, therefore, are responsible for conveying knowledge and skills to parent and caregivers, so as to ensure the patient remains stable after discharge. Their assignments revolve around teaching parents and caregivers how to check vital signs and possible complications, clean catheters and tubes, diapers, ensure skin integrity, switch between decubitus positions, administration of medication, and assess whether the patient is able to feed independently. A social worker must be involved if the caregivers cannot afford the prescribed medication.[11]

Nutritionists assess and prescribe the most suitable diet for patients in home care. To this end, the diet must be tested with the patient for acceptance and signs of rejection such as vomiting, bloating, diarrhea, and constipation, observed. Acceptance of the prescribed care measures is improved when families are involved in patient assessment and consideration is given to their preferences, needs, and ability to afford care.[12]

While the patient is at the hospital, speech and hearing therapists prescribe exercises for oral sensory motor stimulation to adjust the tone, sensitivity, and mobility of speech organs. Speech therapy after invasive mechanical ventilation also includes assessments of masticatory function, phonation, and swallowing based on purpose-specific scales.[13]

Occupational therapists assess the patient's instrumental needs and prescribe functional facilitating instruments not only to manipulate foods but also to assist with the performance of other more general movements to prevent deformity.[14]

Physiotherapists monitor the patient's respiratory support, assess the need for oxygen therapy and, together with a social worker and the family of the patient, consider whether they are able to provide the patient with these technologies at home. If not, the social worker must notify the Health Care Network (HCN) so that the Brazilian Public Healthcare System can make the arrangements to provide the patient with equipment and home care as needed.

Table 1 - Checklist for the dehospitalization of pediatric patients with complex chronic conditions offered care via the Brazilian Public Healthcare System, São Paulo, SP, Brazil, 2019.

Physicians	Psychologists	Nurses	Physiotherapists	Nutritionists	Speech and Hearing Therapists	Occupational Therapists	Medical Engineers	Social Workers
Develop discharge plan: Assess medical criteria; order supplementary tests	Assess patient and family psychosocial status	Train patient family and caregivers on patient hygiene; how to handle feeding tubes; switch between decubitus positions; administration of drugs; preparation for possible complications	Check ventilation support (mode and parameters)	Prescribe the mode of administration of diet to the patient based on method agreed by the team	Assess patient masticatory function, speech, and swallowing	Check whether orthoses or facilitating devices are needed	Check and/ or maintain electronic equipment	Assess socioeconomic and environmental conditions
Produce written description of associated referrals for therapy and prescriptions	Offer psychological care to patients, family, and caregivers until discharge		Train patient family and caregivers on aspiration; how to operate a mechanical ventilator; oxygen therapy; motor physiotherapy exercises; use of BVM in complications; patient positioning	Test the new mode of diet administration in the days prior to discharge	Advise and train family and caregivers on how to administer the prescribed exercises		Sign off and release device for use	When requested, assist in the administration of drugs; materials ordered by the team; mechanical ventilators; oxygen therapy devices - (check a HCN**); - Refer patient to HC***; refer patient to associated therapies
Approve the discharge plan, sign and stamp the documents needed for dehospitalization			Use of MV* by the patient for at least 48h prior to discharge	Advise family and caregivers on how to administer and manage the patient's diet				
Stamp/ Signature:	**Stamp/ Signature:**	**Stamp/ Signature:**	**Stamp/ Signature:**	**Stamp/ Signature:**	**Stamp/ Signature:**	**Stamp/ Signature:**	**Stamp/ Signature:**	**Stamp/ Signature:**
OBS.: All members of the multidisciplinary care team must produce a discharge plan and deliver guidance in written to the patient's family and caregivers.								

* MV: Mechanical Ventilator.
** HCN: Health Care Network.
*** HC: Home Care.

The physiotherapists must also instruct the caregivers about how to perform the procedures that the patient needs, such as aspiration (endotracheal, orotracheal, and nasotracheal), handling mechanical ventilator, oxygen therapy, motor physiotherapy, and operating a bag valve mask in the event of complications.[15]

Medical engineers assess and/or provide maintenance to electronic equipment used in patient care. After each checkup procedure, the medical engineer must sign off the proper forms before releasing the equipment for use. Before the patient is sent home, it is recommended that the mechanical ventilator be tested on the patient for at least 48 hours for surveillance and training purposes.[16]

DISCUSSION

This study found that developed and developing nations have seen an abrupt decrease in child mortality rates. On the other hand, there has been a significant increase in the number of children with complex chronic conditions and a growing rate for hospitalization and need for specific care within this population.[17]

Epidemiology studies have reported a high incidence of diseases of the respiratory tract and described them as the main cause of hospitalization among children with complex chronic conditions in Brazil, followed by tumors and nervous system diseases.[18-20] Furthermore, given their need for ongoing life support technologies, pediatric intensive care units rank among the most costly departments in a hospital's budget.[21]

Before this reality, a new perspective has emerged for the care of patients with complex chronic conditions. Home care has gained emphasis and importance to become an essential tool in patient dehospitalization. According to Feuerwerker & Merhy (2008) and Silva et al., (2010), a cascade of beneficial circumstances may derive from this process: with dehospitalization, the length of hospitalization decreases; if dehospitalization is performed safely, the number of readmissions and complications due to hospital-acquired infection may decrease; and home care may improve patient compliance to treatment.[8,22]

Despite the benefits of dehospitalization, the first three months of a pediatric patient in home care account for the most critical moment, with greater likelihood of the patient having to be readmitted to a hospital. However, interventions

performed with the knowledge and training provided to caregivers have decreased readmissions for symptoms that led to the first hospitalization by 75%.[23]

According to Ndidi et al., (2017), stress caused by hospitalization and the anticipation by patient's family of what home care might entail might contribute to turbulent dehospitalization.[24] Together with inadequate training of caregivers, poor communication between healthcare workers and caregivers, lack of clarity in care plans, and caregiver insecurity may lead to adverse outcomes.[25] The authors of a recent study also added that economically underprivileged families may experience more stress and challenges in the process.[26]

Other authors found that one in five families faced tremendous difficulty with the transition from hospital to home care, an element that may contribute to adverse outcomes such as readmission to hospital. Readmission is an important indicator of failed dehospitalization.[25,27]

Therefore, in line with our study, successful dehospitalization starts from the need to improve the condition of hospitalized patients and must necessarily include patient- and family-centered approaches based on effective communication between the multidisciplinary care team and the patient's family; establish a direct line of contact with primary caregivers; coordinate care with the understanding and support of the patient's family and provide the tools so that they can have every question answered before the patient is discharged from hospital.[28-30]

Family comprehension and support is best understood via the findings published by Rennick et al. (2019). The authors showed that, with time, the parents of pediatric patients with complex chronic conditions develop specialized knowledge to meet the care needs of their children.[17] Therefore, establishing a relationship between healthcare workers and parents/caregivers is essential for the exchange of knowledge needed to improve the care provided to patients to occur.

This is a process that occurs more frequently in clinical practice, although often without a pre-defined process. Therefore, one of the limitations of this study was the lack of scientific evidence to describe what different healthcare workers can do for this group of patients.

It is worth mentioning, therefore, the relevance of having well defined tasks such as the ones in the checklist provided herein, even if they are performed by different healthcare workers in each hospital for reasons of demand and logistics. The organization of teams with clear roles for each member sets the ground for the construction of care and the achievement of common goals.

CONCLUSION

This study offers a checklist for the dehospitalization of pediatric patients uwith complex chronic conditions offered care via the Brazilian Public Healthcare System. We hope that this checklist may serve as a guide to healthcare workers to prevent mishaps in the dehospitalization process and the delivery of guidance in written to patient parents and caregivers.

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