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Harmonic performance of multidisciplinary health teams: humanized hospital discharge

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Abstract

This clinical case report describes and analyzes an experience of prolonged child hospital discharge in a public hospital based on the harmonic action of a multidisciplinary health team. In addition to a literature review, a descriptive and exploratory qualitative study using bibliographic and documentary research techniques was conducted via a retrospective survey in medical records. The results were discussed based on three categories: physical, social, psychological and ethical vulnerabilities of disabling chronic conditions; multidisciplinary teamwork in deinstitutionalization; and home care health policies. We concluded that the process reduced hospitalization time and the number of future hospitalizations, reduced expenses to the health system and reinserted the patient into their community and family environment, thus providing better system structuring and humanized care centered on the individual and family.

Keywords: Deinstitutionalization. Patient care team. Chronic disease. Child. Muscular dystrophies.

Resumo

Atuação harmônica de equipe multidisciplinar de saúde: desinternação humanizada

Este relato de caso clínico descreve e analisa uma experiência de desinternação infantil prolongada em um hospital público a partir da atuação harmônica de equipe multidisciplinar de saúde. Além da revisão de literatura, realizou-se estudo qualitativo de finalidade descritiva e exploratória com utilização de técnicas de pesquisa bibliográfica e documental mediante levantamento retrospectivo em prontuários. Os resultados foram discutidos a partir de três categorias: vulnerabilidades físicas, sociais, psicológicas e éticas das doenças crônicas incapacitantes; atuação da equipe multidisciplinar na desinstitucionalização; e políticas de saúde de atenção domiciliar. Concluiu-se que o processo foi capaz de reduzir o tempo de internação e a quantidade de reinternações futuras, reduzir os gastos ao sistema de saúde e reinserir o paciente na comunidade e no âmbito familiar, proporcionando, assim, melhor estruturação do sistema, bem como atendimento humanizado centrado no indivíduo e na família.

Palavras-chave: Desinstitucionalização. Equipe de assistência ao paciente. Doença crônica. Criança. Distrofias musculares.

Resumen

Actuación armonizada de un equipo multidisciplinario de salud: la deshospitalización humanizada

Este reporte de caso clínico describe y analiza una experiencia de deshospitalización infantil prolongada en un hospital público a partir de la actuación armonizada de un equipo multidisciplinario de salud. Este es un estudio cualitativo, descriptivo y exploratorio en que realizó una revisión de la literatura utilizando técnicas de búsqueda bibliográfica y documental a través de un levantamiento retrospectivo de historias clínicas. Los resultados fueron discutidos a partir de tres categorías: vulnerabilidades físicas, sociales, psicológicas y éticas de las enfermedades crónicas incapacitantes; actuación del equipo multidisciplinario en desinstitucionalización; y políticas de salud de atención domiciliaria. Se concluyó que el proceso logró reducir el tiempo de hospitalización y el número de futuros reingresos, reducir costos al sistema de salud y reinsertar al paciente en la comunidad y en la familia, proporcionando así una mejor estructuración del sistema y una atención humanizada centrada en el individuo y la familia.

Palabras clave: Desinstitucionalización. Grupo de atención al paciente. Enfermedad crónica. Niño. Distrofias musculares.

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According to the World Health Organization (WHO)[1], one of the biggest challenges for health systems worldwide today is the management of chronic conditions, with an uncontroversial link between health and economic development. Chronic conditions are responsible for 60% of all the burden stemming from diseases in the world.

In 2020, the WHO estimated that 80% of developing countries' diseases came from chronic problems, financially burdening their health systems and, consequently, their societies, governments, and families. A chronic condition management plan is lacking throughout the world. Health services are left to treat symptoms only when they appear, because the predominant care model is the one centered on the hospital and medical knowledge[1].

Among the problems growing demand causes for chronic disease care that affect most Brazilian hospitals, long-term hospitalization stands out, characterized by the occupation of beds and the use of expensive financial resources for the entire health system[2,3].

As the length of hospital stay has been used as an indicator of the quality of care provided, these prolonged hospitalizations suggest administrative inefficiency and low quality of care, since the longer-than-expected stay lengths in health units may be due to complications from inefficient care[4].

Several hospitals also face increased costs due to extrapolated daily rates: when a patient exceeds the daily limit established by the Brazilian Unified Health System (SUS), hospitals receive no proportional financial compensation. Moreover, the prolonged stay causes low bed rotations, making institutions unfeasible from a financial point of view[5].

Faced with this problem, public health measures have been focusing on deinstitutionalization. One of the tools for deinstitutionalization is implementing home care policies. Cost reduction is one of its benefits, given that lower hospitalization time means less hospital resources and costly complementary tests are needed, and beds are disoccupied[5].

Pediatrics-wise, technological development contributed to epidemiological changes, with increased survival rates in children with severe conditions—such as premature children or those born with congenital deformities and chronic and degenerative pathologies. This phenomenon promoted the emergence of a new group of children with high demand for health services: children with special needs or, a subgroup, children with complex chronic conditions[6].

The "complex chronic conditions" subgroup covers several categories of diseases that share four similar aspects: 1) significant functional limitations or permanent sequelae; 2) high use of health resources, with recurrent and/or prolonged hospitalization, multiple surgeries and monitoring in several simultaneous specialties; 3) need for health services integration with a family interface; and 4) presence of one or more chronic health conditions. The children in this subgroup end up demanding specific, complex, and constant care, remaining hospitalized for long periods in health services[6].

Congenital muscular dystrophy (CMD) is one of these diseases, integrating myopathies, of usual, although not exclusively, hereditary character (autosomal recessive). Its characteristics include generalized hypotonia (usual at birth), delayed motor development and stationary or slow-progression muscle weakness, and it is evidenced in biopsy as a dystrophic pattern.

Molecular diagnoses to determine CMD subtypes may be relevant for genetic counseling and prenatal diagnosis. However, the clinical heterogeneity of some subtypes often makes them unnecessary since this approach does not affect the natural course of the disease[7].

As children with complex chronic conditions often depend on technology—from power ventilation, medications, or intravenous nutrition, to compensating equipment for vital functions such as dialysis, urinary catheters, and colostomy bags[6]—, long-term hospitalization becomes one of the main models of care.

Because of this scenario, the study of a clinical case of deinstitutionalization becomes relevant. Such a study can evaluate the vulnerabilities inherent to the deinstitutionalization process, seeking to improve patient care and avoid rehospitalization. The importance of reporting cases addressing all these perspectives, humanly and individually, should be emphasized, given the contributions to the improvement of programs by the Ministry of Health (MS) specialized in this care model[8].

This study analyzes the successful deinstitutionalization of a child after a prolonged period hospitalized in a public hospital based on the harmonic performance of the multidisciplinary health team. The specific objectives are: 1) to describe the physical, ethical, social, and psychological aspects in the discharge of a child with CMD; and 2) to present and discuss the multidisciplinary team's management in empowering the family empowerment as a strategic and political component of successful deinstitutionalizations considering the bioethical principle of vulnerability.

Method

This is a qualitative study with descriptive and exploratory character using bibliographic and documentary research methods. The bibliographic research was based on the survey of articles in the PubMed, MEDLINE, and Bireme databases using the descriptors "*deinstitutionalization* and *patient care team* and *chronic disease* and *child* and *muscular dystrophies*." The Boolean search of the terms "*muscular dystrophies* and *home care services* and *child*" was prioritized as a search strategy and the articles published in the last ten years in Portuguese and English language were selected.

The documentary research consisted of a retrospective survey of data in medical records of the case of a child patient with CMD who was hospitalized for six years in a public hospital. The information collected in the 57 medical records included clinical, therapeutic, and observational records made by the multidisciplinary team (composed of a physician, nurse, psychologist, and social worker) from 2012 to 2018.

Three analytic categories were chosen to analyze and discuss the results: physical, social, psychological, and ethical vulnerabilities of disabling chronic conditions; multidisciplinary teamwork in deinstitutionalization; and home care health policies. Regarding vulnerability, William Saad Hossne's was used as the theoretical reference, given its status as a principle of bioethics[9].

Ethical aspects

The child's parents read and signed an informed consent form. Given the disease's disabling effects, resulting in the impossibility of expressing will, the participant's assent could not be collected in any way—verbally or nonverbally. Therefore, a request for waiver from the term of assent was made to the Research Ethics Committee.

Case report

The patient is male, 14 years old, resides in the city of São Paulo, and was diagnosed with CMD (ICD10: G71.0) in 2006, after a biopsy that showed moderate dystrophic muscle changes.

He is the child of non-consanguineous parents, with the following obstetric antecedents: his mother, who is G32PC1A (spontaneous), received prenatal care from the fourth month of pregnancy, totaling five appointments. During pregnancy, she had gestational diabetes and preeclampsia. He was born at term via cesarean section due to preeclampsia, with a weak cry, weighing 3.800 kg and measuring 48 cm. He was discharged from the hospital 48 hours after birth alongside his mother. Breastfeeding was complemented since maternity stay.

Regarding his neuropsychomotor development, he sustained his head at 9 months, sat at a year and a half, and spoke at 2 and a half years. However, he had no sphincter control. Currently, he has a good interfamilial relationship and resides at home with his father, mother, and older sister. His personal history revealed six hospitalizations due to recurrent pneumonia, the last of which is the object of this study.

Prolonged hospitalization

The last hospitalization occurred on June 5, 2012, when the patient was only 6 years old, and lasted until June 25, 2018, when he was discharged after six years.

Initially, the patient was admitted to the ward of a public children's hospital with bronchopneumonia. During hospitalization, he suffered cardiorespiratory arrest, which was reversed after ten minutes, being referred to the pediatric intensive care unit. The patient then presented respiratory failure, requiring mechanical ventilation. Gastrostomy and tracheostomy were also needed in July 2012.

After almost four years, in April 2016, the patient returned to the infirmary, still under the conditions described above. He presented several subsequent infectious urinary, pulmonary, and upper respiratory conditions, which were treated with antibiotic therapy, with remission in September 2016. During this long hospitalization, the patient was in ambient air a few hours a week to attend the hospital's educational program, received oral feeding twice a week, and water four times a day, sitting and using a straw, with the supervision of a speech therapist.

He was discharged with total dependence on care and noninvasive Bipap ventilation due to progressive muscle weakness and pulmonary restriction typical of the disease. The discharge occurred under the conditions of regular external follow-up, with support of a multidisciplinary team, nursing care, physical therapy with tracheostomy supervised by a physical therapist, speech therapy, psychological support, and medical care as needed.

Conduction of the case to home discharge

After the complications during hospitalization, the patient evolved to clinical stability, without any new ones. However, the process for home discharge covered ethical, psychological, structural, and social conditions that depended on more than just medical conduct, prolonging hospitalization for years until the Mistreatment Commission took over the case.

The process of the patient's home discharge was conducted by the Mistreatment Commission of the hospital via the MS's "Melhor em Casa" [Better at Home] program. The commission's members were a nurse, a social worker, a psychologist, and a physician. They attended regular meetings—at least once a month.

The patient's condition during the hospital discharge process was complex and included physical, social, psychological, and ethical aspects.

Physical aspects

CMD is considered a disabling chronic condition due to its degenerative and progressive character, and patients must deal with it for the rest of their lives in a state of vulnerability. CMD is also a condition that increases susceptibility to other pathological conditions, as observed in the case.

The patient was admitted to the Cândido Fontoura Hospital with bronchopneumonia, already having a history of similar pulmonary conditions, with several previous hospitalizations. After compensating for his initial condition, he presented other complications that contributed to decreases in function: an episode of cardiorespiratory arrest, other infectious events, and a humeral fracture. The patient then required ventilatory support, depending on a noninvasive device of continuous positive pressure in the airways, also having to undergo gastrostomy for feeding.

The natural evolution of the disease during these years of hospitalization also contributed to more losses. A practical example was the progressive loss of one of the patient's leisure activities, which was using computers to access the internet. Over time, the patient began to have greater difficulty in handling these devices.

Social aspects

The articulation between the Mistreatment Commission and the Multidisciplinary Home Care Team (EMAD) had some fluctuations at first due to bureaucratic obstacles. The family's residential territory is no longer part of the area covered by the team in question, stalling the home discharge process.

After one year, another EMAD team took over the patient's care, incorporating his family residence into their area of activity and, consequently, initiating the planning of the deinstitutionalization process.

The progression of hospital care to the patient's home required several structural changes so that the residence was adapted to his needs. These changes were monitored by the EMAD, who inspected the house to ensure better conditions for the patient, according to data found in the multidisciplinary team's records.

Large financial investments were also needed to reform the family's home. Everything was paid exclusively by the patient's parents, which further prolonged the discharge process.

Psychological aspects

The parents resisted to the home discharge process at first because of insecurities related to the child's home care in the case of complications. A feeling they often described was that of impotence provoked by the false impression that they could not provide the best care for their child, since the best course of action would be to keep him under the hospital team's sole responsibility.

It is worth clarifying that, before the prolonged hospitalization, the patient's sister was his main caregiver, meaning her time was exclusively dedicated to him. However, the duty of care was shared with the parents during the six-year hospitalization, reducing her overburden. For this reason, the sister also felt uncomfortable about the discharge for fear of having to give up her new routine and return to full-time caregiving for her brother.

The medical records show that such psychological vulnerabilities of the patient's family were managed in frequent psychological consultations. The sessions sought to provoke reflections, develop the main insecurities about home care and, gradually, promote family empowerment in care.

In addition to psychological support, the patient's parents also received training from the nursing and physical therapy teams regarding personal hygiene care, handling of the orotracheal cannula and gastrostomy, as well as possible complications, giving greater confidence for family members to assume responsibility for the patient's home care.

Prolonged hospitalization also created a psychological vulnerability state in the patient. Due to little contact with the environment outside the hospital, whenever he needed to move to another environment, the patient showed extreme anxiety, suffering panic attacks. When asked about the desire to go home, he became apprehensive and tearful.

The patient's psychological approach about his discharge process involved a didactic and pedagogical interaction with the hospital teacher, using his discipline of greater affinity. This approach allowed a playful activity to be used, which consisted of developing a tale about a boy who lived in the hospital and faced his fears when going home. This resource helped the patient deal with the anxiety and fears related to deinstitutionalization, facilitating its acceptance.

Prolonged hospitalization also deprived the patient of interpersonal bonds: after years of confinement in the hospital environment, he became an individual in need of affection and attention, despite the family's frequent visits. He had a good relationship with the other patients in the sector, but they were always discharged a few days later due to improvements in their health condition, whereas he remained hospitalized with no prospect of discharge.

Ethical aspects

Respect for the patient and his family members was an important ethical aspect observed during the deinstitutionalization process.

By recognizing the complexity of the physical, social, and psychological aspects of the patient's condition, aspects of his vulnerability, the multidisciplinary team was able to plan home care according to his health needs. The team sough balance between respecting the patient's initial desires, that of his family members to maintain hospitalization, and the gradual process of empowerment so that they felt safe and became competent care protagonists.

In addition to being complex, the hospital discharge process required several healthcare providers over many years. Home care involves a decision of the patient and family and a necessary restructuring of the team to adapt to this environment. During the process, the team must perform functional activities in their own environment without interfering with the patient's self-determination and freedom. The integration of home care thus required the team's sensitivity about when to suggest discharge. The lack of adequate training for home care could trigger new complications in the patient, sentencing him to an even more complicated and prolonged hospitalization.

Home care thus presents an ethical basis because it was considered as an efficient way to improve the quality of life of a patient whose hospital resources were limited to the disease's treatment, disregarding important issues such as reintegration into the community and family environment. Home follow-up was the core of the support and characterized the program's success.

The revision of all these aspects inherent to the patient's chronic condition, which made him completely vulnerable, shows that the home discharge process was successful because of the multidisciplinary team's harmonic performance, supported by governmental, institutional, and individual pillars. The government, via the Better at Home program, in conjunction with the EMAD, promoted the resources. The capital's public children's hospital, with its multidisciplinary team, ensured the family empowerment process. The attitudes of the individuals involved in this process—the mother, father, sister, and the patient himself—also contributed to a successful deinstitutionalization.

After discharge

Benefits from the discharge included the effective participation of the patient in the family's routine, strengthening affective and relationship bonds. Education was maintained via teachers linked to the Better at Home program and the supplies continued to be provided, in part, by the government and the hospital.

With the training received from the nursing and physical therapy teams, and the guidance of the speech therapist, the family members could adapt home care into their daily lives.

Discussion

Three categories were chosen to discuss and analyze the results: physical, social, psychological, and ethical vulnerabilities of disabling chronic conditions; multidisciplinary teamwork in deinstitutionalization; and home care health policies. The analysis was based on the literature found in the bibliographic survey and in Hossne's theoretical framework on the bioethical principle of vulnerability, as previously described[9].

Disabling chronic conditions

Physical, social, psychological, and ethical vulnerabilities

It can be said that *we are all vulnerable, since we are subject to being injured (in any sense), offended, or hurt, intentionally or not, by agents of any nature (people, animals, weather, etc.) and even by accidents*[10].

Human beings are not only vulnerable, they are also vulnerable in all spheres. Physically, they can get sick; psychologically, their minds are frail; socially, they are subject to social injustices; and spiritually, their internal beliefs can be sectarian. Disease, suffering and disability are thus situations of vulnerability given the susceptibility to harm expressed in the health area and its various spheres[11].

In addition to those of the childhood period, such states of vulnerability intensify frailty scenarios, due to a doubly sensitive condition: in addition to the suffering inherent to the disease itself, these states cause a degree of disability[11].

Age is thus a determinant of vulnerability. Children are usually more susceptible to physical, psychological, and social harm since they depend on others for their care. At younger ages, they are still unable to clearly communicate their feels and wants. During adolescence, puberty and the psychic changes foster risky behaviors, involving themselves in accidents and situations that can damage their physical and mental health[12].

Several states of vulnerability are thus verified in this clinical case report of a child patient diagnosed with congenital muscular dystrophy who remained hospitalized in a public hospital for six uninterrupted years: age, disease, disability resulting from illness, prolonged hospitalization, and, finally, all the suffering caused by each of these conditions.

The various aspects of this disabling condition (physical, social, psychological, and ethical), as described above, cause the patient's vulnerabilities.

Hossne[13] explains that vulnerability is a syndromic condition that can be systemic and multicausal.

The recognition of vulnerabilities must be a reference in all practices of human health care to meet the ethical assumption of the protection of vulnerable subjects and, consequently, plan a care program appropriate to the patient's needs. This means that *vulnerability protection measures should only be considered adequate, from an ethical point of view, when based on the systematic assessment of vulnerability as a syndrome*[14].

In this specific case, the consideration of the systemic and syndromic state of the vulnerability of the patient, family, and health care network itself was essential for the success of the planning and the process of reintegrating the patient to his home by the multidisciplinary team's harmonic and competent performance, as will be demonstrated in the following section.

High-quality clinical care to people with chronic and progressive conditions thus requires attention to the human dimensions of the disease—emotional, social, and moral aspects—that coexist with its biophysical dimensions[15].

Performance of the multidisciplinary team in deinstitutionalization

The concept of health care by a multidisciplinary team goes back to the SUS guidelines, instituted by the 1988 Constitution[16], and to the application of one of its doctrinal principles: that of integrality, which sees individuals as a whole and that must be cared with full consideration for their needs. Health care networks must ensure an intersectoral action between the different levels of care that impacts an individual's health and quality of life[17].

The integration of health care networks seeks to expand the coverage of health service needs by the interaction of various health care practices and the performance of multidisciplinary teams that become strategic and provide structure to health management[17].

The inclusion of other professionals besides those who are directly linked to the disease comes not only with the need to abolish suffering, but also to act in all the dimensions that compose human beings: social, volitive, distressing—in short, all spheres that impact their quality of life[17].

The search for the patient's comprehensive care brings about a new care dynamic that stimulates the sharing of each profession's knowledge, mutual respect between those involved, and new forms of integration of each profession's specificities[18].

Multidisciplinarity is thus a unique and essential approach to comprehensive care, overcoming the isolated, fragmented and individualized practices perpetuated in traditional health care models[19], which tend to medicalize life and suffering, and institutionalize people, generating some unnecessary hospitalizations[20].

From this perspective, the performance of multidisciplinary teams strengthens other health care strategies and mechanisms, such as home care, an alternative to hospital care because it transforms the home environment into a space to produce care and a tool for the deinstitutionalization of care[20].

In this sense, the WHO[1] presented the Innovative Care for Chronic Conditions (ICCC) framework to health systems, which proposes the integration of care between its structuring components and should be made feasible, among other tools, by multidisciplinary teams.

Comprehensive care for people with disabling chronic conditions, as reported herein, thus raises the participation of multiple health workers in multidisciplinary teams to make health care more efficient and cheaper[1].

Regarding the care of CMD patients, due to the absence of a curative treatment, scientific consensus recommends a multidisciplinary approach to delay the progression of the disease and improve the patients' quality of life[20,21] and foster the ability of patient's families to care for them in partnership with health professionals[22].

This case, therefore, ratifies the multidisciplinary team's strategic performance in the deinstitutionalization process and in the continuity of treatment with home follow-ups and the empowerment of the patient and his family members in the promotion of care.

Home care health policies

Home care policies emerged in 1960s, becoming more important in the last 30 years. In this approach, individuals—formerly a mere object of interventions—begin to act as the protagonist of their own care with autonomy [23].

This model of care should be understood as a health service focused on patients and family members in the extra-hospital environment and aim at promoting, maintaining, and/or rehabilitating the patient's health, maximizing their independence, and minimizing the debilitating effects of their pathology [24].

Home care is a viable alternative in view of the current epidemiological change, with a higher prevalence of chronic and degenerative diseases and more demand for health services [25,26]. Actions to decrease morbidity and mortality rates related to prolonged hospitalization are also important, thus reducing the risks of hospital infections caused by prolonged stay in institutional environments [20].

Better at Home was thus developed to regulate home care services. The program is an initiative of the federal government via SUS, aiming the integral care of patients in the extra-hospital environment to promote, maintain, treat, and rehabilitate health, involving family members in the process [20].

Home care is conducted by EMAD teams, which are usually composed of nurses, physicians, nursing assistants, and social workers. Other professionals such as psychologists, nutritionists and speech therapists can also make up the Multidisciplinary Support Teams (EMAP). These frequency of home visits by these professionals depends on the patients' condition [20].

The program aims to expand home care, involving all levels of health care—from basic health units to complex hospital services [26-28].

Home care provides patients with benefits such as humanized care closer to their family, assisting in the process of recovery, reducing the risk of contamination and infection in hospital environments, and making more beds available [20].

Finally, considering that one of the core axes of home care is deinstitutionalization, and that EMAD teams operate this service—as provided for in the Ministry of Health Ordinance 962/2013 [29], this case report verifies the success of the multidisciplinary team's performance in hospitalization is supported by the institutionalization of such health policy.

The only case report on patients with CMD found in the literature describes the case of a 26-year-old man, whose transition from childhood to adulthood required the planning of his health care, involving home infrastructure changes—especially with the use of assistive technology to maintain his independence in mobility and facilitate the caregiver's assistance—and the support to family members with the coordination of multiprofessional care at home [30]. Public policies should, therefore, include the promotion of home care based on partnerships with health professionals [23].

Final considerations

The advantages of reduced hospitalization time include reduced costs for institutions and, for patients, lower risk of hospital infections due to long stays and return to the community and family environment.

The shift of human resources to this type of multidisciplinary care and the transformation of patients and family members into protagonists of care and the structuring of the entire public health system results in less beds being used and the humanized care centered on individuals and the family.

The case demonstrated that the multidisciplinary team's harmonic performance was fundamental for the successful deinstitutionalization process of a child patient affected by a chronic disabling disease. The recognition of his vulnerabilities as a syndromic and systemic state was necessary for the adequate planning of care for his health needs.

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Participation of the authors

Lissa Horiguchi participated in the literature review, description, interpretation, and analysis of the clinical case. Lourran Lenci Carvalho wrote the article. Edson Umeda conceived the study theme and design. Marina Borba developed the conception of the study's theme, design and outline, and critically reviewed the manuscript.

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